UNDERSTANDING ACADEMIC RESEARCH PRIORITIES AND INDIVDUAL CHOICES ABOUT PALLIATIVE CARE AND ADVANCE CARE PLANNING

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UNDERSTANDING ACADEMIC RESEARCH PRIORITIES AND INDIVDUAL CHOICES ABOUT PALLIATIVE CARE AND ADVANCE CARE PLANNING

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This dissertation compiles three papers that focus on challenges in research on and practice of palliative care. The first chapter reports on a survey of 61 leading academic researchers in palliative care, who were asked their opinions on research priorities and barriers to better research in the field. Qualitative methods were used to extract the seven leading research recommendations and four barriers to better research generated by the purposively interdisciplinary group.

The next two chapters use the Wisconsin Longitudinal Study to test hypotheses about the correlates and triggers of advance care planning (ACP) in older adults, cross-sectionally and, for non-planners, at a follow-up seven years later. The results presented in Chapter 2 identify several dimensions of health that are associated with formal and informal ACP cross-sectionally. Over time, changes in health have little affect on the likelihood of a non-planner completing ACP by Time 2, seven years later.

In Chapter 3, I applied theory of social diffusion to ACP, hypothesizing that the planning status of a spouse or sibling would increase a non-planner's likelihood of doing planning by Time 2. The cross-sectional analysis found strong associations between spouse only and spouse and sibling status on formal and informal ACP of the focal individual, respectively. Over time, however, having a spouse or sibling with formal (but not informal) ACP affected the focal individual's likelihood of going on to do planning, but having both a spouse *and* sibling with formal ACP at Time 1 had an

attenuating effect on the focal individual's likelihood of planning.

In the final chapter I draw connections between the three research activities and suggest directions for future research. Most pressing is the need for evaluation of existing education programs to support older adults as they complete ACP and the development of novel programs targeting individuals who are least likely to engage in ACP. The growing body of academic research on factors that facilitate ACP should be translated into more effective supports for conversations about end-of-life health care.

BIOGRAPHICAL SKETCH

Emily Kahoe Chen studies the social and psychological aspects of chronic disease, focusing on ways to improve treatment and outcomes in older adults. She has an MA in Human Development from Cornell University and an AB in the Growth and Structure of Cities from Bryn Mawr College.

To Toby, who has punctuated my study of the end of life with all the amazing milestones of a very young life, and Eric, for your support.

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Study, University of Wisconsin-Madison, 1180 Observatory Drive, Madison, Wisconsin 53706 and at http://www.ssc.wisc.edu/wlsresearch/data/. The opinions expressed herein are those of the authors.

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PREFACE

I came to graduate school with the belief that solutions exist for complex problems, and that the role of the researcher was to identify and promote these solutions through evidence. The challenge facing our society that drew my interest was the growing population of older adults in the United States. Since the baby boomers began celebrating their 65th birthdays in 2011, about 10,000 Americans turn 65 years old every day, a trend that will continue for two decades. Currently, Americans who live to 65 can expect to live about 18 more years (Administration on Aging, 2010). This intersection of demographics and innovations in health care is changing the social and economic landscape. As consumers, workers, and family members, there are simply *more* older adults, both in absolute terms and as a share of the population, than there have ever been before.

Older adults are a great resource; their longevity translates into more workers and volunteers, activists and consumers, family members, and friends. But poor health, specifically chronic diseases -- including life-threatening conditions like heart disease, cancer, respiratory diseases, and stroke, as well as non-life-threatening conditions like osteoarthritis, hypertension, and diabetes -- impinge on the quality of life of older adults. Symptoms of these conditions, such as pain, fatigue, and breathlessness, as well as troubling symptoms resulting from the illness experience, like sleep disturbance, anxiety, and depression, are for many people the daily reality of old age; about 80% of older adults have at least one chronic condition, and about half have two or more chronic conditions (Centers for Disease Control and Prevention, 2011).

The most common chronic conditions do not limit themselves to quarterly doctor's appointments; the medication regimens, activity limitations, special diets or therapies, and the uncertainty that comes with living with a chronic disease spills over into daily life. For this reason, the study of chronic disease is not solely the responsibility of medical or health science research. There are myriad social processes that surround and involve older adults with chronic illness, ranging from caregiving to communication to planning for the end-of-life. Social scientists across disciplines can bring their methodological, theoretical, and context expertise to explore crucial social and psychological features of chronic illness in this population.

In this dissertation, I have completed three papers that bring to bear social science theory and methods on research questions related to palliative care, a promising practice for improving quality of life through managing symptom burden in older adults with serious illness. The World Health Organization defines palliative care as:

> …an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (World Health

Organization, n.d.)

Research on palliative care is conducted across many disciplines, including medicine, nursing, health services, social work, and other social sciences. This interdisciplinary attention to palliative care brings a broad base of support promoting the practice of palliative care, but the division of researchers has made the field prone to silos, even more than is common in academic research. In addition, relative to other areas of medicine, palliative care has been poorly funded (Glefman, Du, & Morrison, 2013), suggesting that research in palliative care has been guided more by what projects manage to obtain funding rather than a comprehensive and strategic research agenda that reflects the scientific priorities of the field. Largely as a result of these challenges, and in response to the growing need for palliative care by older adults with serious illness, an up to date and deliberately interdisciplinary research agenda is crucial to maximize the utility of academic research for palliative care.

The first chapter of this dissertation reports on a survey of leading academic researchers in palliative care. A purposive and interdisciplinary sample of 61 “thought leaders” were asked about their opinions for most pressing research priorities in the field, as well as barriers that they felt were preventing more and better quality research on palliative care from being conducted. Previous research agendas for palliative care have been created over the last 15 years. This updated research agenda distinguishes itself in several ways. First, we asked respondents individually, using a semi-structured interview format that allowed open-ended responses. Responses were transcribed and coded using qualitative methods. Consequently, specificity of research recommendations was maintained that might have been lost in a group process. This

research agenda is also unique because it asked about barriers to research. Our survey is the first able to comment not only on what should be done, but also on why those goals have not been accomplished yet.

At the time of the Thought Leader Survey, I was planning the remaining portion of my dissertation. I had identified newly available data from the Wisconsin Longitudinal Study that could shed light on advance care planning (ACP) behaviors in older adults. The remainder of the dissertation was planned based on standard research practice; I had reviewed the literature, identified gaps, and settled on the appropriate method and dataset to test relevant hypotheses. However, based on my experience interviewing researchers in the Thought Leader Survey and reviewing their transcripts, in which participants spoke passionately about the importance of palliative care, the challenges of implementation, and the need for more research, I began to think about the second and third papers as the way in which I, as a researcher, could respond to the call for better research on palliative care.

The topic of the second and third chapters, ACP, was explicitly named by only a few respondents in the Thought Leader Survey. However, a commonly endorsed barrier to better research on palliative care was the lack of public and professional understanding about palliative and end-of-life care, and an overall ignorance about and reluctance to discuss death and dying. This problem, along with the call for more research and education on the public understanding of palliative and end-of-life care, was also the leading recommendation of palliative care practitioners in a related project activity, a research-to practice consensus conference on the topic of palliative care (Pillemer, Reid, Chen, Riffin, & Kenien, 2013).

I believe that these issues of public misperceptions of palliative care, lack of knowledge about end-of-life, and a cultural reluctance to think about and discuss serious illness and dying are deeply entwined with the discussions about and legal planning for end-of-life health care that may or may not occur. In Chapters 2 and 3, I report on research that tested hypotheses about the correlates and predictors of ACP in a longitudinal survey of older adults in Wisconsin. In Chapter 2, I tested the effects of health cross-sectionally and how health changes over time might trigger ACP in people without planning at Time 1. There was variation in which measures of health were associated with which types of planning, but in general, sick people plan, but people with declining health seem not much more likely to plan than their peers with stable health. This finding echoes others' research, underscoring the important role of health in ACP, and extends existing research by highlighting a strong association of chronic conditions with informal ACP, a dimension of health that has not been explored.

In Chapter 3, I applied theory of social diffusion to ACP, hypothesizing that the planning status of a spouse or sibling would increase a non-planner's likelihood of doing planning by Time 2. The cross-sectional associations were in keeping with what social diffusion theory would expect: people who did planning were related to others who did planning, with formal ACP affected by spouse only and informal ACP affected by both spouse and sibling. Over time, however, having a spouse or sibling with formal (but not informal) ACP affected the focal individual's likelihood of going on to do that type of planning. The influence of having both a spouse *and* sibling with formal ACP at Time 1 was an attenuated effect on the focal individual's likelihood of

planning. Apparently, for non-planners, heterogeneity in the planning status of family members is more conducive to engaging in planning in older adulthood than a case in which the focal older adult is the only "hold out" without formal ACP.

With regard to the bigger picture of research on palliative care, the research presented in Chapters 2 and 3 serves two functions. First, the pattern of results lends support to specific theories of change of ACP -- namely, cues to action in the health belief model and theory of social diffusion. This is helpful because research on the theory of change at work in ACP is underdeveloped, and being able to understand ACP within theoretical models will strengthen future research and interventions.

A second important function of the chapters on ACP is that they highlight characteristics of non-planners, information that is essential for effectively targeting intervention to increase rates of ACP. With relatively high rates of ACP in older adults (Morrison & Meier, 2004; Silveria et al., 2010; Teno et al., 2007), non-targeted education or planning-support campaigns will be wasting resources on people who have already done ACP or would go on to do ACP without support. Developing effective interventions to encourage and support individuals who are reluctant to engage in ACP is a small but important part of the solution to American cultural resistance to the topic of death and dying. It was my intention that the research on ACP in Chapters 2 and 3 could help inform effective interventions.

I conclude the dissertation with a final chapter to make connections between findings of each paper and list implications for future research.

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CHAPTER 1

FUTURE DIRECTIONS AND CHALLENGES FOR RESEARCH ON PALLIATIVE CARE: A THOUGHT LEADERS' RESEARCH AGENDA[1]

[1]Portions of this chapter have been published as the article in Journal of Palliative Medicine © 2014 copyright Mary Ann Liebert, Inc.

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Abstract

Purpose: We surveyed a national sample of thought leaders to identify the most pressing research needs and barriers to conducting research in palliative care.

Design and Methods: Semi-structured telephone interviews were conducted with a purposive, interdisciplinary sample of leading researchers in palliative care in the US. In-depth interviews were completed with 61 thought leaders, transcribed and then analyzed to identify major themes using qualitative methods.

Results: The most frequently-named recommendations were to improve research designs and outcome measures, and to do more research on understudied and underserved populations, healthcare systems and delivery models, symptom management, practitioner education, cost-effectiveness, communication, and caregivers. Thought leaders identified four barriers to improved research in palliative care: funding, researcher workforce, the public and health care providers' perception of palliative care, and challenges associated with doing research with participants who are seriously ill. Open-ended responses revealed the sense of urgency on the part of researchers regarding the importance of improving research in palliative care, as well as fears that the field will not be prepared to meet the challenges of an aging society.

Implications: Given the potential for palliative care to improve the well-being of older adults with serious illness, gerontological researchers and organizations across disciplines should respond to the identified priorities to help address these knowledge gaps.

Keywords: end-of-life care, hospice, death and dying

Introduction

Due to advances in medical treatment and management of many diseases, people are surviving for relatively long periods of time with conditions that in the past were fatal after a short period of illness. Life-limiting or chronic illness that persists for months or years is now a typical feature of older adulthood (Improving End-of-Life Care, 2004). As a result, palliative care – that is, a focus on symptom management, spiritual, and psychosocial support for patients and families as they cope with serious illness – is widely seen as a promising approach to align the health care received by older adults with their wishes for symptom-focused, non-invasive, and supportive care (Steinhauser et al., 2001).

Palliative care constitutes a relatively new and rapidly expanding field that is poised to be in high demand as the population ages and lives longer with serious illness. To meet this need, research on palliative care should focus on the most pressing gaps in knowledge (Morrison, 2013). Several reports and documents from professional meetings over the past 15 years have attempted to summarize and guide palliative care research, highlighting weaknesses in existing literature and topics in need of attention (Field & Cassel, 1997; Improving End-of-Life Care, 2004; Aziz, Miller, & Curtis, 2012). However, to our knowledge the field of palliative care lacks a state-of-the-art, empirically-based agenda that identifies priorities for future research.

It is the premise of this article that social science research approaches used to measure opinions and attitudes can and should be used to establish research priorities in palliative care. The present study employed a survey of a relatively large and

interdisciplinary sample of leading palliative care researchers ("thought leaders"), coupled with an in-depth qualitative methodology to provide a detailed list of research priorities and barriers to research in palliative care. The resulting research agenda reflects a current and broadly-sourced set of priorities that palliative care researchers and investigators new to the field should consider when planning or seeking to justify their work.

Methods

We conducted a survey of thought leaders in palliative care from November 2012 to January 2013. A purposive sample of 77 thought leaders was assembled through three sources. First, the Research Portfolio Online Reporting Tools of the National Institutes of Health (NIH RePORTer) was searched for all NIH grants in the last five years related to palliative care. The principle investigators of these awards formed the core of the sample. The research team enriched this list by nominating additional high-profile researchers who were not recipients of NIH funds for their work on palliative care. In recognition that the RePORTer sample was skewed toward physicians rather than nurses or social scientists, individuals from these and other disciplines were added by the research team in an attempt to balance the purposive sample. The resulting interdisciplinary sample consisted of researchers from the fields of medicine, nursing, social work, sociology, psychology, and health services research.

The semi-structured interview asked respondents to identify knowledge gaps, make research recommendations, and list barriers to improved research. When the survey was introduced, interviewers provided a definition of palliative care that

included the full spectrum of services, from concurrent care (i.e., when a patient receives curative therapies alongside psychosocial care and symptom management from a palliative care team) through formal end-of-life or hospice care. Respondents were told, "We are interested broadly in research priorities for persons with advanced chronic illness who are not at the end-of-life, as well as for individuals receiving hospice or end-of-life care." The first question was, "What, in your opinion, are the most important research priorities in the field of palliative care? Another way to think about this question is: 'To achieve an optimal system of palliative care, what is the most pressing gap in our knowledge?'" Interviewers probed for more research priorities until the respondent offered no new recommendations.

Next, the major themes of research recommendation gleaned from review articles on palliative care (a related project activity) were used by the interviewer as prompts to generate more research recommendations. If the respondent had not made recommendations related to one or more of the following five themes – 1) improved research methods, 2) measurement issues, 3) interventions, 4) understudied populations, and 5) "other specific topic areas" – the interviewer asked, "Do you have any recommendations for improving knowledge in the area of [theme]?" Finally, respondents were asked, "What do you see as the major barriers to improving and expanding palliative care research?" Interviewers probed until the respondent offered no more barriers. All interview protocols were reviewed by the Institutional Review Board of Cornell University.

Members of the sample were first contacted by email and then by telephone to schedule the survey. Eleven thought leaders did not respond after multiple contact

attempts and five declined to participate citing busy schedules. With the exception of seven participants who requested an email version of the survey, all remaining participants were interviewed over the telephone. Interviews were completed with 61 individuals. Including both refusals and non-respondents in the denominator, the overall response rate was 79.2% (61/77). Review of transcripts confirmed that this number of interviews was sufficient to reach saturation of main themes.

Respondents' characteristics are shown in Table 1. Half of respondents were physicians or teaching in a school of medicine. Approximately 30% were from the field of nursing, with the remaining respondents from the social sciences, public health, social work, or health services research.

Data analysis

All phone interviews were audiotaped and transcribed. Transcripts were verified for accuracy and, along with the email responses to the survey, loaded into Dedoose qualitative analysis software. Two investigators (EC and MW) sequentially reviewed the transcripts to identify statements that related to the two major concepts targeted *a priori* by the survey: research recommendations and barriers to research. Disagreements were resolved through discussion. This line-by-line open coding resulted in a set of in vivo codes related to the research recommendation and barrier concepts. Satisfied that all data related to these two concepts were represented in the set of codes, two investigators (EC and KP) combined the research recommendations and barriers into discrete categories (i.e., selective coding). Codes were constructed to appropriately name the categories. The resulting categories were then presented to all investigators for verification as a form of member checking. Using feedback from the

project team, some categories were divided or merged.

Results

The main themes that emerged from the interviews are reported below, with selected quotations to illustrate each theme. The two recommendations that addressed research methods are presented first, followed by the seven recommendations or knowledge gaps about specific topics within palliative care. The number of respondents who endorsed each research recommendation is shown in Table 2.

Recommendations to improve research methods in palliative care.

1) Improve and/or explore non-RCT study designs to expand and bolster the evidence base for palliative care. Thought leaders overwhelmingly expressed a desire for more rigorous research in palliative care, namely, more randomized controlled trials (RCTs) and comparative effectiveness research to demonstrate the benefit of specific interventions or palliative care in general. However, respondents conceded that the challenging nature of palliative care populations may preclude traditional RCTs and urged researchers to explore alternative research designs, like quasi-experimental, observational methods.

> We need to come up with ways to do scientific projects that are not necessarily randomized control trials. I think that it's really hard to do randomized controls and it may not be the most efficient way to collect data. [Respondent 26]

Noting the challenges of recruiting from this target population, one respondent suggested prospective research to improve access to participants, such as creating registries of individuals who would consider participating in research in the future. Multisite research collaborations that pool patient populations or engage in common data collection of palliative care practices were also suggested as a way to improve

palliative care research.

Another frequent recommendation related to research methods was to improve and expand the use of advanced statistics in order to analyze complex data. Respondents raised issues related to longitudinal and organization-based research, like techniques for handling missing data, multi-level modeling, and growth curve modeling. Respondents also recommended that palliative care researchers should utilize propensity scores or instrumental variables, techniques that help account for group differences in quasi-experimental data.

In addition to quantitative data, qualitative and mixed methods approaches were also recommended. Respondents said that more qualitative research could complement quantitative research, contribute to the development of theory, and capture the unfolding experience of living with serious illness in a way that inspires innovation.

> I think mixed methods have to stay pretty high on the [agenda] because I'm a little worried that we still impose our preconceived models on the area. Unless we do some pretty sound qualitative work, along with quantitative, we may be missing the boat. [Respondent 6]

In both quantitative and qualitative data analysis, thought leaders encouraged future palliative care researchers to ask "why" and "how" questions so that we can begin to understand not just the outcomes of palliative care, but the processes and mechanisms through which these outcomes are achieved. Palliative care was described as "a bit of a black box" where "unpacking and understanding exactly what it is that's made a difference" is important [Respondent 31].

Finally, when making recommendations about study designs and data analyses,

a cross-cutting theme was that palliative care research should be relevant and intelligible to clinicians. “I think a challenge that we have is when researchers get involved in complex modeling of data, and present their results, they aren't always able to go back to, what does this mean clinically?” [Respondent 13].

2) Select or construct treatment and outcome measures that are psychometrically sound, clinically meaningful, and policy-relevant. Thought leaders recommended that investigators pay more attention to measurement when conducting palliative care research. This recommendation encompassed improving conceptualization and measurement of outcomes, as well as clarifying and promoting a shared understanding of what palliative care means, for both providers and the public. “There's still a lack of definitional clarity, conceptual clarity. It's still not obvious how to operationally define these various terms that are used interchangeably -- notably end-of-life care, palliative care, hospice care, and so forth” [Respondent 51]. Respondents thought that clearly articulating what palliative care entails is necessary for rigorous evaluation of its effects.

Respondents talked about the value of patient-reported outcomes and thorough assessment, but were keenly aware of the need to minimize patient burden. One respondent noted that “the assessment tools are exceedingly cumbersome to use in a clinical setting with frail patients who typically don’t have a lot of time” [Respondent 7]. Evaluating pediatric populations, the cognitively impaired, and patients with communication impairments was deemed especially challenging. More research on item response theory and the reliability of different types of proxy reports was suggested as a way to improve measurement in patients receiving palliative care.

Respondents named several specific areas in which measurement tools needed to be improved, including tools to ascertain physical and psychological symptoms, quality of life, quality of death and dying, and instruments that are validated across diverse race and ethnic groups.

> So many of the outcomes and factors that you're looking at in palliative care research are subjective; it's not like you can get a blood test for pain or for nausea. You are ultimately going to be dependent on patients' reports, and those are much more sensitive and may vary significantly across populations. To improve measurement, you really need to get much more sub-population specific to say that, this pain scale has been validated in the Hispanic population, or this pain scale has been validated in the Asian American population. [Respondent 35]

The lack of consensus or convention about which measurement tools to use was also cited as an obstacle to be overcome. Some respondents complained about the lack of psychometrically validated measures, while others stated that there were ample measures, but that they were not consistently utilized by researchers in the field. This difference is likely related to the specific type of research conducted by respondents (e.g., oncology versus communication), but illustrates that this cross-section of researchers in palliative care all place a high priority on and acknowledge the difficulties of sound measurement tools for this population.

Similar to the research recommendation that advanced statistical methods or study designs should be interpretable to clinicians, thought leaders emphasized the importance of using standardized outcome measures that have relevance to different stakeholder groups, including policymakers.

> We must address the needs of the different stakeholders, including policy stakeholders. What do they need to know from research in order to change the

> rules of the game for palliative care? There's got to be a balance, a slate of measures that represents what counts as convincing evidence to the different people who play an important part in the life of palliative care. [Respondent 54]

Research recommendations and knowledge gaps in palliative care

1) More research is needed on understudied and underserved populations.

Respondents called attention to the growing racial, ethnic, and religious diversity in the United States, and urged more research on the intersection of diversity with palliative care. Respondents lamented the ways in which differences in the race, ethnicity, language, or other dimensions of culture might be leading to disparities in the quality of care that patients receive.

> There are clear and dramatic differences in the care people receive based on race and ethnicity, but we're really at our infancy in understanding which of those differences are actually differences based on patient preferences, differences that should be honored and supported, and which of them are disparities based on inadequate communication across cultural boundaries or inadequate understanding that need to be understood and eliminated. [Respondent 31]

Thought leaders also named non-cancer conditions as being highly understudied. Specific non-cancer conditions nominated as needing more research were neurological illnesses, dementia, heart disease, renal failure, and lung disease. Many respondents related that individuals with multiple comorbidities constitute a particularly challenging understudied population. Despite the frequency of patients with multiple illnesses, thought leaders saw existing research on palliative care as focused on single illnesses. There was concern about the lack of research on how palliative care could help patients with multiple chronic conditions that are not necessarily seen as life-threatening at the time, but that will eventually lead to the patient's death.

> The understudied group would be groups of people who don't have a specific diagnosis by which you would say they are at risk of dying. It's people who are living with chronic conditions. I know that may sound strange, but they are underserved relative to palliative care. … It's one thing to say that people with congestive heart failure don't get good palliative care and focus on that, but how about the people without a diagnoses who are living with symptoms that could be alleviated and lead to a better quality of life? [Respondent 2]

Pediatric and young adult patients were also identified as an under-researched population. Specific issues in the care of younger patients were ethical issues and a lack of pediatric-specific intervention studies that induce clinicians to extrapolate from adult studies when caring for children. Although the absolute number of children and young adults in need of end-of-life care is relatively small, thought leaders lamented the lack of targeted palliative care and/or hospice resources available to patients and families in this devastating circumstance.

Thought leaders named several understudied populations that could be described as patients who experience economic and other barriers (i.e., geographic, provider shortages) to palliative care. "There are still huge pockets of discrepancies in access to clinicians skilled in symptom management and end-of-life care. The majority of patients who need palliative care never get it" [Respondent 8].

2) Do more health systems research. Thought leaders identified a knowledge gap in palliative care around health systems research, research concerned with the application, delivery, and outcomes of palliative care beyond symptom management at the patient level. One researcher recommended that more research be done to "address not just the patient outcomes, but the system outcomes, doing studies that capture the economic implications of what we're doing and the cost savings and workforce issues of providing that care" [Respondent 10]. One thought leader's succinct

recommendation was representative. “[The field of palliative care needs more] health services research that defines the varied core elements of palliative care in different venues and outcomes associated with those components” [Respondent 41].

Thought leaders raised the issue of reimbursement specifically as an important area for more research, including how reimbursement affects access to services.

> I think [a research priority is] looking at the various reimbursement systems and how they either incentivize or disincentivize palliative care. When you look at the Medicare benefit, the hospice benefit, how those interact with Medicaid long-term care at the state level… it’s a critically important issue. And then private insurance, for patients under 65 that aren't eligible for Medicaid, that are hospice candidates, how do those reimbursement streams work together? [Respondent 3]

With regard to research on health systems, thought leaders frequently raised the importance of identifying and implementing best practices in the delivery of palliative care within and across health care settings. As one respondent put it, “how best to design healthcare systems and delivery models to bring the right care to the right patient at the right time and the right place” [Respondent 36]. Thought leaders also acknowledged that implementing already-identified best practices remains a challenge.

Respondents also identified research gaps around the integration of systems, settings, and providers. Moving between settings and providers was identified as a risky transition for many patients, but ways to improve transitions or increase continuity for patients receiving palliative care was deemed a knowledge gap. Respondents also recommended that more research be done on palliative care delivery models that break from the traditional inpatient care models for cancer patients, including delivery of palliative care in home, primary, and subspecialty care settings.

A prominent theme in innovation in care delivery was how non-physician or non-specialist staff could be utilized to provide palliative care. Respondents were cognizant of the lack of specialists despite the growing need for palliative care. Research on models of staffing and care delivery that could provide more high-quality services for lower cost was recommended. Non-physician (and also lower-cost) staff such as advance practice nurses, pharmacists, home health aides, and nursing assistants to help deliver palliative care seemed a promising prospect for respondents. Thought leaders also recommended research on how palliative care teams are composed; what combination of physicians, nurses, social workers, chaplains, and other professionals provides the best care most efficiently?

3) Generate a stronger evidence base for symptom management. Thought leaders identified knowledge gaps around the management of specific symptoms. Respondents were aware that symptom management is often ineffective and/or not based on rigorous evidence. They acknowledged that clinicians were doing their best, but suffered from the lack of high-quality studies on the effectiveness of different treatments.

> One of the things I was always struck by is how little trial data are available for many of the symptom-oriented approaches that we talk about. … What is generally taught in palliative care curricula at this point [is often] unclear and unproven. I think it would be very helpful, and these are studies that I conceptualize as not that difficult to do. [Respondent 35]

Many thought leaders named pain and pain control as an ongoing concern and area for research, but non-pain symptoms were also deemed to be an important research priority. Respondents recommended more research on effective therapies for non-pain symptoms and the testing and dissemination of effective protocols.

Frequently-mentioned non-pain symptoms or disorders included dyspnea, nausea, fatigue, delirium, anorexia/cachexia, depression, and spiritual distress. The study of symptom clusters or syndromes, in contrast to research on single symptoms, was also highlighted as a research gap, despite the reality that most patients experience multiple symptoms.

With regard to pain, respondents hoped to see advances in drug therapies available (i.e., non-opioid pain treatments), as well as more research on how targeted or tailored therapies and protocols could be used in pain management. “We only have one effective class of drugs for analgesia and that's opioids and they have terrible side effects. We need more research on safer effective analgesics” [Respondent 36]. Neuropathic pain was named as a particular area of concern. More basic science was urged on all fronts in order to develop new agents and targeted interventions.

4) Do research on practitioner knowledge and education. Thought leaders recommended that more research be done on how to educate health care providers about palliative care so that they could better meet the needs of patients with serious incurable illness. A prominent theme was how to effectively and efficiently educate and support practitioners who deliver palliative care. “I think what's really missing is [research] to identify staff needs in terms of support and training on all staff levels in order to be able to effectively implement a palliative care model” [Respondent 57]. Evaluating the impact of education was also a research recommendation.

> Does palliative care education and training make a difference? If we want to educate doctors about this field and have it in the curriculum in medical school… can we show that it makes a difference? We need research to see the impact of educational approaches on physician knowledge and practice. [Respondent 48]

5) Study the effectiveness and cost-effectiveness of palliative care. Many thought leaders recommended that more research be done on the financial cost and any savings associated with palliative care delivery, not as a primary tool to argue for its use, but as an important supporting factor.

> You have to show that you're providing a benefit to patients and their loved ones. If you start with costs, health systems may be impressed, but you'll turn the public against you because it will quickly degenerate into a conversation about rationing and death panels. But if you first show that quality of life is improved, I think you have a solid foundation to move forward. The next step would be to look at potential cost savings, because it has to be a "both/and" proposal: that we improve quality of life, and as a nice side effect reduce costs. [Respondent 44]

A related knowledge gap identified by respondents was the lack of research on the possible wide-ranging benefits of palliative care, ranging from reduced symptom burden to improved access to appropriate medical care to improved adherence with therapies. "[It is] important to articulate that there is a value to improved function and quality of life" [Respondent 1].

6) Do more research on communication. Respondents perceived a knowledge gap around communication in palliative care. More research was recommended on the best ways to educate providers to communicate with patients and families and on interventions that could enhance communication and understanding in all directions. Respondents talked about how important conversations can fail to convey or convince a patient about the seriousness of a situation, due to cultural barriers, word choice, and other issues.

> I think we have to be really aware of the language we use when working with patients and families around awareness, because using "dying" and "end of life", it just doesn't trigger for some people what you are talking about. I think

> there is a lot of work to be done in communication and language and understanding patient and family perspectives of how they see the experience, and what language is most useful to them in planning, across the spectrum of illness. [Respondent 56]

Respondents recommended experimental research on framing effects and on how language influences decision-making in preferences for end-of-life care.

7) Study caregivers. Research on caregivers and effective interventions to support informal caregivers of patients receiving palliative care was also identified as a knowledge gap. Thought leaders emphasized the difficult but extremely important role of family and informal caregivers for patients with serious illness.

> The greatest burden of care for patients with serious illness who fall into the palliative care world falls on informal or family caregivers. They just suffer greatly. We know very little about that, but those families are keeping people out of the hospitals. Those families are doing the care at home. [Respondent 46]

More research was recommended on interventions to support caregivers in two major ways. First, thought leaders encouraged the development of interventions to support the psychological well-being of caregivers, citing burnout, psychiatric morbidity, and complicated grief as common sequelae associated with this stressful role. Second, respondents wanted to see more research on caregiver education and "technical support." This recommendation was in response to the greater responsibilities placed on informal caregivers of patients receiving palliative care at home, both medical, like running feeding systems or administering intravenous fluids, and social or logistical, such as making home modifications and managing home care staff.

Barriers to improving or expanding research on palliative care. Following

the questions about research recommendations and knowledge gaps, respondents were asked what they perceived were barriers to improved and expanded research in palliative care. The four major themes that emerged are listed below. The number of respondents who endorsed these themes is shown in Table 2.

1) Funding. A large majority of respondents listed funding as a major barrier. Respondents acknowledged the current climate of limited federal research dollars and a current emphasis on bench science over systems research. One respondent described the intensive effort required to assemble competitive grant applications that, because of limited funds, have a small likelihood of being funded. “My colleagues are just totally frustrated. They don't know where else to turn because they're doing their best on these applications and they can't do the work” [Respondent 22]. Thought leaders related the lack of funding to a bleak future for palliative care. “If we don't get federal funding right now, I don't want to know what it's going to look like in the future” [Respondent 13].

In addition to limited funding in general, many commented on the lack of a “home” for palliative care or symptom-oriented research at the NIH, despite the designation of National Institute for Nursing Research (NINR) as the lead institute for end-of-life issues. The lack of reviewer expertise across NIH, something that might be achieved through a dedicated study section for grants related to palliative care, was listed as a funding-related barrier, as well as the type of research being proposed in palliative care as compared to other topics. “When a palliative care grant is being reviewed with a hypertension grant and chemotherapy grant, it's really hard to stack up because of the immaturity of the science. The science in those areas is so much more

mature" [Respondent 31].

2) Researcher workforce. Thought leaders identified a lack of well-trained investigators as a major factor limiting progress in the field, but also acknowledged that few resources were available for junior researchers who wanted to progress in the field. Both formal research training opportunities, like fellowships for physicians, and informal opportunities, like being mentored by senior researchers, were listed as factors that inhibit the development of a robust workforce. For researchers with clinical responsibilities, the struggle to carve out time to do research was identified as a common barrier impeding progress in the field.

3) Public and professional understanding and perception of palliative care. A third barrier to improved research was a misunderstanding and related resistance to palliative care from both the medical community and the general public. The lack of consistent definitions and implementation of palliative care, hospice care, and other end-of-life related terms contributed to what thought leaders described as widespread misunderstanding of the topic. American culture's discomfort with and reluctance to discuss death was also named as a barrier to palliative care research.

4) Challenges of study population and topic. Patient recruitment and retention was named as an unsolved problem that palliative care researchers face. Doing research in clinical settings was also seen as presenting unique challenges to investigators, in part because research goals or protocols may not always overlap with usual clinical practice. In addition, overly-cautious institutional review boards (IRBs) were listed as a barrier to improved research. Some thought leaders felt that the additional protections for palliative care populations that some IRBs required were

based on an inaccurate perception of the vulnerability of seriously ill patients or recently-bereaved families.

Discussion

The knowledge gaps and recommendations for research identified by this sample of thought leaders converged around a central theme: research should support high quality, evidence-based palliative care services that are made available to all people in all settings. The significant attention directed toward improving research methods reflects a self-critical acknowledgement that more methodologically strong studies are needed to influence clinical practice and health policy. The recommendations that research be done on symptom management, communication, and practitioner education, when taken together, communicate respondents' vision that palliative care should be both based on good evidence and delivered skillfully by practitioners. Recommendations for more research on understudied and underserved populations and on health systems research reflect thought leaders' concern that the current reach of palliative care is limited, and that barriers based in health disparities and poor integration of health care systems should be studied so that they can be overcome.

Unlike the wide range of research recommendations, thought leaders listed comparatively few barriers to improved research in the field of palliative care. The two main barriers were a shortage of funding and lack of trained investigators. The variety in research recommendations could be attributed to disciplinary differences or differences in expertise. However, the dominance of funding and workforce as barriers to improving research in palliative care implies that these barriers affect researchers

across the field in similar ways.

The direct quotations used above have the primary purpose of illustrating thought leaders' responses to the survey questions. However, we hope the quotations also convey how passionately the thought leaders argued for dramatic expansion of research on palliative care. Most respondents were extremely aware of where and how palliative care was failing patients, both the ones it serves without knowing the best protocols, and the ones it never reaches at all because of provider shortages, poor communication, or the barriers of patient and provider ignorance. Thought leaders consistently linked research gaps to limitations in the practice of palliative care; lack of an evidence base for a protocol or failing to understand care transitions were discussed in terms of how patients and families are affected.

There are no other recent systematic research agendas for the field of palliative care with which to compare our results. However, research recommendations or areas of research focus can be inferred from two other recent projects that summarized and commented on the state of the field, the 2004 NIH State of the Science on End-of-Life Care Consensus Conference (Improving End-of-Life Care, 2004) and the 2011 NINR Science of Compassion summit (Aziz et al., 2012). Space constraints preclude detailed comparisons, but we highlight three differences between the present research agenda and previous work.

First, one-third of respondents in this study nominated cost-effectiveness research as an important topic for future research in palliative care. Cost-effectiveness was not a leading research recommendation in either consensus conference. Second, thought leaders in this study recommended research on and identified as an important

research barrier what they described as the culture of medicine and American culture in general, in which the goal of prolonging life is predominant and a goal of quality of life is less widely accepted. Again, neither of the two recent consensus conferences on palliative care included this topic as a research priority.

Third, advance care planning (ACP) was identified as a knowledge gap by only six thought leaders in this study. The 2004 State of the Science Conference did not include ACP in their list of suggested research areas. However, in the 2011 NINR conference proceedings, advance care planning was combined with communication to form a leading research recommendation, and was the topic of two of the six resulting articles (Green & Levi, 2012; Waldrop & Meeker, 2012). Respondents in our study did recommend more research on communication in palliative care, which might include discussions around ACP. Taken together, this pattern of findings suggests that future research on ACP be linked to communication, which is the higher-level and more pressing research area for palliative care.

Finally, we believe that our integration of survey and qualitative methodologies has several advantages that complement other efforts to determine priorities in palliative care and may serve as a model to others working to determine research agendas for other fields. First, this methodology avoids limitations of consensus conferences, on the one hand, which are time and resource intensive, and reviews of the published literature, on the other, which may fail to capture the full interdisciplinary breadth of palliative care research or be out of date because of the delay involved in the writing and peer-review process. Second, by using survey methods, this study solicited the opinions of many more researchers than the typical

number involved in a consensus conference or in the development of white papers, and also asked them to respond individually, based on their own impressions, rather than as a group or in response to a specific set of documents.

Implications for Aging Research

As is reflected in our sample, most research on palliative care is conducted by medical personnel. Physician and nurse researchers are well-suited to conduct research on many of the topics listed in the research agenda reported in this article. However, we believe that the efforts of social scientists can also help to advance this research agenda. For example, thought leaders' complaints about the culture of medicine and the United States, their questions about the impact of physician education, and concerns regarding how patient racial and ethnic diversity affects access to care are all issues that social scientists have the skills to answer.

The barriers identified by respondents portray a challenging setting for conducting palliative care research. Given the reality of funding and our cultural unwillingness to talk about death, improving research on and the quality of palliative care will requiring the efforts of many skilled researchers. Social scientists concerned with the well-being of older adults should consider mounting research programs around these pressing and understudied topics, with the assurance that practitioners are eager for evidence, and that advancing the availability and quality of palliative care has the ability to improve the quality of life for older adults living with chronic illness, as well as for people with serious illness and at the end of life.

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Table 1. Respondent characteristics

	Number of Respondents (%) (n=61)
Field	
Medicine	30 (49.2%)
Nursing	17 (27.9%)
Social science	11 (18.0%)
Other	3 (4.9%)
Institution Type	
School of medicine	37 (60.7%)
School of nursing	8 (13.1%)
University	4 (6.6%)
School of public health	3 (4.9%)
Other	9 (14.8%)
Degree	
MD	27 (44.3%)
PhD	14 (23.0%)
PhD/RN	12 (19.7%)
Advanced nursing degree	5 (8.2%)
Other	3 (4.9%)

Table 2. Research Recommendations and Barriers to Research in Palliative Care

	Recommendations to Improve Research Methods	Number of Respondents Endorsing Category (%) (n=61)
1	Improve and/or explore non-RCT study designs to expand and bolster the evidence base for palliative care. *Design studies appropriate to the phenomena and population of interest; use advanced statistical method and mixed or qualitative methods; study mediators, moderators, and mechanisms; communicate results in meaningful ways*	39 (63.9%)
2	Select or construct treatment and outcome measures that are psychometrically sound, clinically meaningful, and policy-relevant. *Develop and use clear definitions of palliative care and related terms; improve and use patient- and family-reported outcomes, including proxy reports*	39 (63.9%)
	Research Recommendations and Knowledge Gaps	
1	More research is needed on understudied and underserved populations. *Study patients with non-cancer conditions; patients with comorbidity; pediatric patients; ethnic, racial, and cultural minorities; the medically underserved*	45 (73.8%)
2	Do more health systems research. *Work to understand outcomes of palliative care in non-hospital settings and/or when delivered by non-physician providers; study what makes effective interdisciplinary palliative care teams; study effect of when palliative care is introduced on outcomes; determine effects of reimbursement for services on palliative care*	42 (68.9%)
3	Generate a stronger evidence base for symptom management. *Do more RCTs and comparative effectiveness research on non-pain syndromes and symptoms; develop new treatments and agents for symptom management; improve and disseminate best practices and protocols for managing distressing symptoms*	37 (60.7%)
4	Do research on practitioner knowledge and education. *Measure the effects of practitioner training and education in palliative care; study how provider beliefs and attitudes affect palliative care referrals*	23 (37.7%)
5	Study the effectiveness and cost effectiveness of palliative care. *Understand the far-reaching costs and benefits of palliative care for patients, families, and health systems*	22 (36.1%)
6	Do more research on communication	21 (34.4%)

	Develop interventions to promote communication; study the effect of language on communication between providers and patients	
7	Study caregivers. *Do research to understand the psychological and instrumental needs of caregivers; design interventions to meet these needs*	19 (31.2%)
Barriers to Research in Palliative Care		
1	Funding *Lack of research funding and lack of expertise and commitment to palliative care at the NIH are barriers to better research.*	42 (68.9%)
2	Researcher workforce *Lack of training programs for researchers, fellowships for physicians, and the competing clinical demands of practitioner-researchers limit the pool of high quality palliative care researchers.*	27 (44.3%)
3	Public and professional understanding and perception of palliative care. *Reluctance of the public and medical professionals to discuss or accept death has resulted in fear and confusion about palliative and end-of-life care.*	18 (29.5%)
4	Challenges of study population and topic.	15 (24.6%)
	Special research protections and other considerations that need to be made for patients receiving palliative care and the difficulty of studying serious illness both make doing research in this field difficult.	

CHAPTER 2

EFFECT OF HEALTH AND CHANGES IN HEALTH ON ADVANCE CARE PLANNING IN OLDER ADULTS

Abstract

Objectives: To examine the association of five measures of health (recent hospitalization, self-rated health, health-related quality of life (HRQOL), major health events, and diagnosis of chronic conditions) with the likelihood of having formal or informal advance care plans at age 64, and to assess, for participants without ACP, how these measures of health and changes in health affect the likelihood of completing ACP seven years later.

Methods: This study uses the 2004 and 2011 waves of the Wisconsin Longitudinal Study. Logistic regression equations were estimated to assess the association between measures of health, changes of health measures, and the outcomes of interest, formal and informal ACP. Two models test the association between health measures and ACP for all participants (Study 1). Additional models test the association between health measures and changes in health for participants with no formal or informal ACP, respectively, at Time 1 only (Study 2).

Results: In Study 1, different Time 1 measures of health were significantly related to formal and informal ACP at Time 1. Respondents who experienced major health events were more likely to do informal ACP, but chronic conditions were associated with greater likelihood of informal but not formal ACP. Contrary to the hypothesis, poorer self-rated health was associated with lower odds of both formal and informal ACP at Time 1. In Study 2, for respondents without formal ACP at Time 1, HRQOL at baseline was the only measure of health that predicted likelihood of formal ACP at Time 2. For respondents without informal ACP at Time 1, only number of chronic conditions was associated with likelihood of informal ACP at Time 2. Measures of

changes in health between Time 1 and Time 2 did not significantly predict formal ACP status at Time 1, with one exception: likelihood of informal ACP at Time 2 was predicted by declines in self-rated health between Time 1 and Time 2.

Discussion: Diverse measures of health have different associations with formal and informal ACP. Contrary to a central hypothesis, *changes* in cross-sectional measures of health status have little influence on the likelihood of an individual to complete ACP relative to health at Time 1, suggesting either that impressions of individual health are anchored in earlier states and relatively insensitive to change, or that individual health is weak predictor of ACP relative to other influences. Further research on ACP should include measures of health that are more specific and objective than self-rated health.

Introduction

Advance care planning (ACP) refers to the formal and informal actions individuals may take to document and communicate their wishes for medical care. ACPs are used to guide medical care when a patient is not able to make decisions due to unconsciousness, impaired communication, or cognitive impairment. Formal ACPs are any legal document, such as an advance directive, living will, or Durable Power of Attorney for Health Care, that records an individual's wishes about health care or designate a proxy decision-maker for health care. Informal ACP refers to conversations or discussions about wishes for medical care with important others or health care providers. A combination of formal and informal ACP is increasingly recommended (Sudore & Fried, 2010), especially among older adults, for whom decisional incapacity is common as the end of life approaches (Kim, Karlawish, & Caine, 2001; Silveria, Kim, & Langa, 2010). The benefits of ACP are wide ranging. ACP has been shown to align the treatments patients receive with the types of treatments that they had documented a wish to receive at the end of life (Silveria et al., 2010) and predict many measures of end-of-life care quality, such as hospice use and ICU admission (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). ACP has also been shown to facilitate proxy decision-making (Braun, Beyth, Ford, & McCullough, 2008; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007) and reduce end of life health care costs (Elsayem et al., 2004; Morrison, et al. 2008; Smith, et al., 2003).

Advance directives are becoming more common among older adults, especially those living in nursing homes (Jones, Moss, & Harris-Kojetin, 2011; Resnick et al., 2009), but they are still under-utilized, with representative surveys

reporting that approximately one third of older adults lack formal ACP (Morrison & Meier, 2004; Silveria et al., 2010; Teno et al., 2007). Increasing the rate of ACP completion is a public health goal (Field & Cassel, 1997; Morhaim & Pollack, 2013). Existing interventions to encourage ACP through patient education have been shown to have modest effects (Bravo, Dubois, & Wagneur, 2008; Jezewski, Meeker, Sessanna, & Finnell, 2007; Tamayo-Valázquez et al., 2010). Therefore, understanding the mechanisms and dynamics of ACP has the potential to improve interventions and increase the reach of ACP.

Despite the fact that ACP deals with health, the effect of health on the likelihood of completing ACP has not been systematically explored. Literature on ACP has focused on demographic attributes associated with planning, and the effect of stressful life events as a catalyst of planning. For example, female gender, White race, more years of education, more advanced age, and being married have been shown to be positively associated with ACP (Black, Reynolds, & Osman, 2008; Bravo, Dubois, & Pâquet, 2003; Carr & Khodyakov, 2007; Carr, 2012a; Carr 2012b; Hopp, 2000; Kahana, Dan, Kahana, & Kercher, 2004; Kwak & Haley, 2005). Stressful life events that have been shown to be associated with an increased likelihood of planning include hospitalizations in the previous year, having a spouse or parent experience a painful or difficult death (Carr, 2012a; Carr & Khodyakov, 2007), and the presence or recent diagnosis of a medical condition for oneself or a friend or relative (Pollack, Morhaim, & Williams, 2010). Although some of these events are related to health, research has not identified what types of health events or dimensions of health are associated with which types of ACP.

This paper adds to the existing literature with two studies that test how different measures of health are associated with different types of planning (i.e. formal or informal ACP), and how changes in health over time may be more important to triggering planning than cross-sectional measures of health. Study 1 tests the association of five measures of health (hospitalizations, self-rated health, health-related quality of life, chronic conditions, and major health events) with the respondent's likelihood of completing formal or informal ACP at Time 1, with specific hypotheses for whether or not each measure of health is expected to be associated with formal ACP, informal ACP, or both types of planning. Study 2 focuses on the likelihood of people without ACP to complete planning by a follow-up survey seven years later. Statistical models in Study 2 compare the relative predictive power of changes in health (between Time 1 and Time 2) over baseline health (at Time 1) on the outcome of Time 2 ACP.

Conceptual Framework

Prior research on correlates of ACP have attributed differences in rates of ACP across socioeconomic and race groups to Fundamental Cause Theory (Carr, 2012b), wherein groups with fewer resources and access to resources are globally less able to attain good health through health behaviors, disease prevention, and treatment (Link & Phelan, 1995). Other research has suggested that ACP is a type of stress response or coping mechanism, wherein meaningful events prompt individuals to express their wishes for their own end-of-life experience (Carr 2012a; Carr & Khodyakov, 2007; Pollack et al, 2010). In studies that focus on the process of completing ACPs, Fried and colleagues (Fried, Bullock, Iannone, & O'Leary, 2009; Fried et al., 2012) have

applied the Transtheoretical Model (Prochaska, Redding, & Evers, 2002), a theory of health behavior change, to end-of-life health care planning (although see also, Westley & Briggs, 2004).

This study conceptualizes ACP as a health behavior, that is, something people do to improve their health and well-being (Karl & Cobb, 1966). Literature on ACP suggests that, beyond the influence of social position, an individual's experiences or evolving attitudes play a role in his or her likelihood of planning. Cues or critical incidents, such as a hospitalization or experience with another's illness or death, may trigger planning, either directly or indirectly, as an individual's sense of susceptibility or beliefs in benefits of ACP change as a result of that event.

Although several models of health behavior include constructs similar to triggers or cues, the most developed is the concept of "cue to action" as described in the Health Belief Model (Becker & Maiman, 1975; Janz & Becker, 1984; Rosenstock, 1974). A cue to action is an event or experience that triggers a health behavior. Cues to action can be internal or external, ranging from symptoms (internal cue) to interpersonal interactions to mass media campaigns (external cues; Janz & Becker, 1984; Becker, Haefner, Kasl, Kirscht, & Maiman, 1977). McBride, Emmons, and Lipkus (2003) elaborate on the concept of cues to action by proposing three pathways through which a cueing event can become a full-fledged "teachable moment," which enhances motivation, self-efficacy, and acquisition of skills, facilitating the desired health behavior. In their formulation, effective cueing events must (1) increase perceptions of susceptibility or outcome expectancy, (2) prompt strong affective or emotional response, or (3) redefine or alter social role. In that health states or health

events are likely to impact individuals in all three of these ways, I propose that different components of individual health and changes in health may serve as effective cues to action for ACP.

In the study of other health behaviors, different indicators of health and health events have been found to be trigger subsequent health behaviors. For example, a review by Demark-Wahnefried and colleagues found that cancer diagnosis has been associated with the adoption of a variety of health behaviors, including physical activity, fruit and vegetable consumption, and smoking cessation, continuing at least 1 year post-diagnosis (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005), and a population-based study found greater likelihood of cancer survivors meeting physical activity guidelines compared to respondents without a cancer history (Bellizi, Rowland, Jeffery, & McNeel, 2005). A review of studies of smoking cessation also found that "teachable moments," such as hospitalization, disease diagnosis, or abnormal test results, often served as catalysts to patients to quit smoking (McBride et al., 2003).

The type of behavior that a health event may cue is likely based on the health event. For example, hospitalization for a routine procedure may trigger completing formal ACP because these forms are made available to patients upon admission, but may not trigger conversations with family members (i.e. informal ACP). Conversely, progressively declining health or chronic health problems that lack acute events or hospitalization may trigger informal ACP, perhaps through casual conversations with family caregivers over time, but not any formal documentation of a person's wishes. The meaning imbued into the health event, the expectations associated with the health

state, and the resources to do planning or external expectation of planning (e.g. in a cancer care setting) may all affect the health behavior that is cued.

In the studies described below, I use five measures that capture different dimensions of health: hospitalizations in the last 12 months, self-rated health, health-related quality of life (HRQOL), count of three common chronic conditions (diabetes, arthritis, hypertension), and count of major health events (heart attack, stroke, cancer diagnosis). Recent hospitalization is included because of the serious health events that often accompany an in-patient stay, as well as the requirement of the Patient Self-Determination Act for hospitals to provide all admitted patients with information about advance directives, inquire if the patient has an advance directive, and, if so, to add the document to the patient's file. I include the single-item measure of self-rated health, a remarkably consistent predictor of mortality (Benyami & Idler, 1999), which suggests that poor overall opinion of one's health would be linked to ACP, as individuals reporting poor self-rated health may have a sense that end-of-life is approaching. A major health event, defined here as a reported stroke, heart attack, or cancer diagnosis, indicates an acute and potentially life-threatening experience, and may therefore be a plausible trigger of end-of-life planning. An individual's HRQOL (operationalized here by the Health Utilities Index, a weighted composite measure of functional status) may be salient to choices related to ACP; experiencing limits to physical ability may prompt individuals to consider making their wishes known, both about end-of-life preferences and other circumstances of personal care and residential preference (Black, Reynolds, & Osman, 2008). Finally, chronic illness may be more likely than acute illness to disturb a person's sense of well-being (Freund & McGuire,

1999), highlighting vulnerability and disrupting previously-held beliefs about self-hood (Bury, 1982).

In addition, changes in these measures of health, specifically declines in health, may serve as a cue to action in a way that stable health -- even stable poor health -- may not. Long-term poor health may reflect chronic conditions that are not seen as imminently life threatening, and thus may not substantially increase the likelihood of ACP among healthy individuals of a similar demographic profile. In contrast, declines in health or HRQOL, or increases in the number of chronic conditions or major health events over a short period of time may encourage individuals to put their affairs in order in anticipation of continued decline or death.

In the context of ACP, few studies have addressed how different dimensions of individual physical health are related to ACP or how changes in health may trigger ACP. This paper extends the existing literature on correlates of ACP by exploring the extent to which several different measures of health may serve as cues to action or triggers of planning in older adults. Study 1 and Study 2, outlined below, focus on how different measures of health and changes of health, respectively, predict formal and informal ACP. Based on the meaning and implications of different health measures, I hypothesize that hospitalization and major health events will be associated with formal ACP, chronic conditions will be associated with informal ACP, and that HRQOL and self-rated health will be associated with both types of planning. In addition, I hypothesize that declining health between Time 1 and Time 2 will make respondents more likely to complete planning by Time 2 than would be expected by Time 1 health measures alone.

Methods

Data

The WLS has followed a random sample of 10,317 graduates of Wisconsin high schools since 1957. The survey has collected data on school achievement, employment, family, and more recently, topics related to health and well-being. In the 2004 and 2011 waves of data collection (referred to as Time 1 and Time 2, respectively), the Wisconsin Longitudinal Study (WLS) asked a series of questions about end-of-life preparations. Respondents were approximately 64 and 71 years of age in the 2004 and 2011 waves, respectively. The interview (conducted by phone in 2004 and in person in 2011) contained many questions on health. Of particular value to the present study, the 2011 wave of the WLS is the first large-scale longitudinal measurement of ACP, providing a window into the stability of health and ACP status for this sample over a seven year period.

In 2004, the end-of-life module was administered to a sample of respondents (approximately 70%, n=4967; Figure 1). The first hypothesis focuses on these respondents. In 2011, all respondents were asked about end-of-life plans. The second and third hypotheses focus on respondents who reported either no formal (n=1972) or no informal (n=1314) ACP at Time 1, about half of who (52% and 55%, respectively) went on to report that form of ACP in 2011.

Consideration of Missing data

In the planned analyses, cases are lost for two reasons. The first source of lost cases is missing data from participant refusal or failure to complete a portion of the

survey. Variables in this analysis are from both the telephone (2004) or in-person (2011) portion of the data collection, and the booklet of additional questions that were left with the participant after the in-person interview or mailed to the home of telephone interviewees. Non-responses were extremely uncommon (<1%) for questions on the telephone or in-person portion of the interview. However, 11% (n=784) and 13% (n=752) of respondents with completed telephone or in-person interviews failed to complete their "leave behind" paper survey in 2004 and 2011, respectively. Second, respondents were lost to follow-up between Time 1 and Time 2. Of respondents without FACP at Time 1, 24% (n=465) were lost to follow-up by Time 2. Of respondents without IACP at Time 1, 25% (n=329) were lost to follow-up by Time 2. The leading causes for failure to resurvey the respondents were refusals (~75% of missing) and death (~15% of missing).

Formal and Informal Advance Care Planning

The outcomes of interest in this study – formal and informal ACP – are derived from three questions asked in the WLS. The module was introduced with: "Now I am going to ask you some questions about the later years in life. Have you made plans about the types of medical treatment you want or don't want if you become seriously ill in the future?" Participants were then asked: 1) Have you discussed your health care plans and preferences with anyone?", "2) Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? (This is sometimes called a Durable Power of Attorney for Health Care)", and "3) Do you have a living will or an advance directive? (This is written instructions about the type of medical treatment you would want to receive if

you were unconscious or somehow unable to communicate?).” For the purposes of this study, a respondent has made informal ACPs if he or she reports having discussed health care plans and preferences with anyone. The measure of formal ACP corresponds to a participant either having made legal arrangements or having written instructions.

Because formal and informal ACP are often completed at the same time, and each has been shown to affect the likelihood of completing the other (Carr & Khodyakov, 2007), an indicator of formal or informal ACP at Time 1 will be included in the logistic regressions that predict the other type of planning at Time 2.

Known Correlates of Advance Care Planning

All models adjust for respondent age (in years), sex (male is reference), educational attainment (in years), marital status at Time 1 (separated or divorced, widowed, and never married, with married as the reference group), and number of children, all of which have been associated with ACP (Carr & Khodyakov, 2007; Hopp, 2000; Kahana et al., 2004). Although graduate respondents are all approximately the same age, age of respondent will be included in order to be consistent with other research on ACP. Race is also an established predictor of ACP, but it will not be included in this analysis because the WLS is nearly exclusively White (<.5% non-White).

Indicators for death of a spouse or parent between Time 1 and Time 2 are also included as controls when testing for what factors trigger ACP by Time 2 for respondents without ACP at Time 1; others’ deaths, including both the poor-quality death of a spouse or parent (Carr & Khodyakov, 2007) as well as “good deaths” that

were at home and free from pain (Carr, 2012), are also associated with ACP. The indicator variable for widowhood between Time 1 and Time 2 identifies respondents who reported any status other than “widow/widower” at Time 1 and a marital status of “widow/widower” at Time 2. At Time 1 and Time 2, each respondent was asked if his or her mother and father were alive. The indicator for parental death identifies respondents who reported a living mother or father at Time 1 who was reported deceased at Time 2.

In all models, I control for trait conscientiousness, death avoidance, and physician control beliefs because of the association between attitudes and beliefs with ACP (Carr & Khodyakov, 2007). Conscientiousness was measured with 6 items. A representative question was, “To what extent do you see yourself as someone who does a thorough job?” These items were averaged to create a single item, ranging from 1 to 6, where higher values correspond to higher levels of conscientiousness. The summary score was created for respondents who answered at least three questions; missing values were imputed to the mean of valid items before summing. A single question “To what extent do you agree that you avoid thinking about death altogether?” (1=Agree Strongly to 6=Disagree Strongly) measures death avoidance. Because higher score on this measure indicates less death avoidance, higher score reflect a greater willingness to think about death. Respondents were asked, “To what extent do you agree that you would rather have your doctor make the decisions about what's best for your health than to be given a whole lot of choices?” Responses ranged from 1 (Agree Strongly) to 5 (Strongly Disagree). Higher scores indicate stronger endorsement of patient (versus physician) control in medical decisions.

Health

Five measures of respondent health are included in the models, measured at Time 1 and as change scores between Time 1 and Time 2 (with the exception of recent hospitalization, which was not collected at Time 2). The five measures all pertain to health, but capture different constructs.

Hospitalization is denoted with an indicator identifying respondents who reported a hospital admission lasting at least one night in the 12 months preceding the Time 1 survey. Hospitalization has been associated with ACP (Carr & Khodyakov, 2007).

Self-rated health is a measure of perceived health. Self-rated health was solicited from all respondents by asking "In general, would you say your health is: excellent, very good, good, fair, or poor?" Self-rated health is included in this study as a continuous measure from 1 to 5 where 1 is excellent health and 5 is poor health.

Health-related quality of life (HRQOL) was measured in the WLS by the Health Utility Index Mark 3 (HUI3; Horsman, Furlong, Feeny, & Torrance, 2003). The HUI3 covers the domains of vision, hearing, speech, mobility, dexterity, emotions, cognition, and pain. Each domain is evaluated with five or six questions that ask about the respondent's ability to accomplish specific tasks in the past four weeks. For example, to evaluate vision, the participant is asked, "During the past 4 weeks, have you been able to see well enough to read ordinary newsprint without glasses or contact lenses?" Subsequent questions ask about the ability to read with glasses, to recognize a friend at a distance with and without glasses, and to see at all. Respondents' ability or limitations within each domain are combined to create a single

HRQOL score that represents overall function, with weights for both severity of impairment and domain that are taken from the general population's opinion on the relative value of function. For example, moderate to severe daily pain is weighted so that it detracts from the overall HRQOL score more than moderate to severe vision impairment. The single item measure of HRQOL that results is a continuous score ranging from 0 to 1 where 0 is a state of health equivalent to death and 1 is perfect health.

A measure of *chronic conditions* was created based on whether or not the respondent reported one of more of three conditions that are common but often manageable with low to moderate levels of symptom burden: high blood pressure or hypertension; diabetes; or pain, stiffness, or swelling in the joints. For the first two conditions, participants were asked if a doctor had diagnosed them with the condition; arthritis-like symptoms were based on self-report only and did not ask about receiving a diagnosis. A score of chronic conditions was created where 0 corresponds to having none of these health conditions and 3 to having all of them.

Following Moorman and colleagues (Moorman & Carr, 2008; Moorman, Carr, Kirchhoff, & Hammes, 2012), a measure of *major health events* was created based on whether or not respondents reported that a doctor had ever told them that they had heart problems (heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems), a stroke, or cancer (cancer or a malignant tumor, not including minor skin cancers). This measure ranges from 0 to 3.

Analysis plan: Study 1

Study 1 includes all respondents who were asked about ACP at Time 1. I

estimate binary logistic regressions with formal and informal ACP as the outcomes, including all the control variables described above, to test the following hypotheses about associations of the five measures of health with ACP at Time 1 (see Figure 2):

- Hospitalization in the last 12 months and major health events are positively associated with formal ACP.
- Chronic conditions are positively associated with informal ACP.
- Poorer self-rated health and worse health-related quality of life are associated with increased likelihood of both formal and informal ACP.

Analysis plan: Study 2

The second goal of the present research is to consider how changes in these health measures may trigger ACP in older adults without ACP. I hypothesize that poor health at a single time point may not be as predictive of ACP as *declining* health, in that declining health would be more likely to raise questions of mortality than poor health that is stable over time. To illuminate this issue, Study 2 focuses on respondents without ACP at Time 1. Formal and informal ACP at Time 2 are the respective outcomes of two nested models. Each nested model first estimates the effect of Time 1 health status on likelihood of Time 2 planning (partial model). A subsequent full model adds measures of changes in health. Comparison of the partial and full models provides a test of the following hypotheses (see Figure 2):

- Hospitalization in the 12 months prior to Time 1 and major health events at Time 1 are positively associated with formal ACP at Time 2, for respondents without formal ACP at Time 1.
- Chronic conditions at Time 1 are positively associated with informal ACP at

Time 2, for respondents without informal ACP at Time 1.

- Poorer self-rated health and worse health-related quality of life at Time 1 are associated with increased likelihood of both formal and informal ACP at Time 2, for respondents without planning at Time 1.
- Decline in health status between Time 1 and Time 2 is associated with additional increase in odds of ACP (increase in major health events increasing likelihood of formal ACP, increasing chronic conditions increasing likelihood of informal ACP, and poorer self-rated health and health-related quality of life increasing likelihood of both types of planning).

All models control for the known predictors of ACP, described above. The full model that includes changes in health between Time 1 and Time 2 also controls for becoming a widow or widower and for having the other type of ACP at Time 1 (e.g. controlling for having formal ACP at Time 1 when predicting informal ACP at Time 2).

In addition to the statistical significance and magnitude of the odds ratios for the variables representing changes in health status, the relative explanatory power of the full over the partial models is tested by a likelihood ratio test, comparing the difference in the -2LL between the models to a chi-square statistic with four degrees of freedom (corresponding to the difference of the number of parameters between the models).

Results

Study 1

Sample Description

Table 1a shows respondent characteristics for the 4967 respondents who were asked about ACP at Time 1. The left panels compare the characteristics of those with formal ACP to those without. The right-most panels compare respondents with and without informal ACP. Compared to those without, respondents who reported formal or informal ACP had more years of education, were more likely to be married and have spent a night in the hospital in the past 12 months, were more conscientious, less death avoidant, and endorsed beliefs about patient (versus physician) control over important medical decisions. The group reporting informal ACP had a larger proportion of females. Respondents who reported having either type of ACP also reported better self-rated health than non-planners (non-significant trend for informal ACP, p=.087), but also reported more experiences of cancer. Respondents with informal ACP had a larger proportion of diagnoses of chronic condition, especially arthritis-like complains. Finally, respondents who made either formal or informal ACPs were more likely to have the other type of ACP in place than those without.

Bivariate Results

Some of the predictors are moderately correlated. For example, among all respondents who were asked about ACP at Time 1, self-rated health is moderately correlated with health utilities (r=-.459), chronic diagnoses (r=.363) and major health events (r=.328). All other correlations between health measures (not shown) are less than .3. The outcomes, formal and informal ACP, are also moderately correlated (r=.391).

Multivariate Models: Health as a Predictor of ACP at Time 1

Formal ACP

The first two columns of Table 3 show results of the two binary logistic regression equations that predict formal and informal ACP, respectively, at Time 1. I hypothesized that recent hospitalizations, more major health events, poorer HRQOL, and poorer self-rated health would all be associated with formal ACP at Time 1. Hospitalizations and self-rated health were both significantly related to formal ACP, and major health events were marginally related (p=.064). However, the direction of the association of self-rated health and formal ACP was not as predicted: reporting poorer self-rated health decreased the odds of formal ACP (OR=0.89). Also contrary to the hypothesis, HRQOL was not significantly associated with formal ACP.

Informal ACP

I predicted that chronic conditions, poorer HRQOL, and poorer self-rated health would increase the odds of informal ACP at Time 1. All were related to informal ACP, although the association of HRQOL was only marginally significant (p=.08). Similar to the association of self-rated health and formal ACP, the association of self-rated health and informal ACP was not in the expected direction; respondents reporting better health were more likely to report informal planning than those in worse health. Not hypothesized, but significant, were the impact of recent hospitalizations and major health events on informal ACP (ORs=1.37 and 1.20 respectively).

Study 2

Sample Description

Table 1b compares the characteristics of respondents who did not report formal or informal ACP at Time 1, based on whether or not they went on to complete that type of ACP at Time 2. For example, the left side of the table characterizes females, individuals who became widows or widowers between T1 and T2, and respondents who reported informal ACP at Time 1 as overrepresented in the group of respondents who completed formal ACP by Time 2. In contrast, respondents without informal ACP at Time who completed informal ACP by Time 2 were slightly younger, more educated, more willing to think about death, and more supportive of patient (vs. physician) control than their counterparts with no IACP at Time 2. Respondents with informal ACP at Time 2 were also more likely to report hospitalization, arthritis, and heart problems at Time 1 than respondents who continued to report no informal ACP at Time 2. The group that went on to complete informal ACP was also more likely to have had formal ACP in place at Time 1.

Bivariate Results

Similar to the pattern of bivariate associations in Study 1, among respondents with no formal ACP at Time 1, self-rated health was moderately correlated with Time 1 health utilities (r=-.437), chronic diagnoses (r=.356), and major health events (r=.327). Correlations between self-rated health and these measures of health for respondents who reported no informal ACP at Time 1 were -.440, .348, and .289, respectively. Formal or informal ACP at Time 1 shares significant but very small correlations with informal (.082) and formal (r=.171) ACP, respectively, at Time 2, for respondents who did not have that type of ACP in place at Time 1.

Multivariate Models: Time 1 Health as a Predictor of ACP at Time 2 for Respondents

with no ACP at Time 1

Formal ACP

The four right-most columns of Table 6 show results of the logistic regression equations to predict formal and informal ACP at Time 2 for respondents who reported no ACP of that type at Time 1 and who had complete data at Time 2 (n=1507 and n=985, respectively). Hypotheses predicted that hospitalizations prior to Time 1, and major health events, HRQOL, and self-rated health measured at Time 1 would be associated with formal ACP at Time 2, for people without formal ACP at Time 1. However, in the model, only HRQOL is significantly related to formal ACP at Time 2, with poorer HRQOL at Time 1 predicting formal ACP at Time 2.

Informal ACP

I predicted that chronic conditions, HRQOL, and self-rated health at Time 1 would be associated with informal ACP at Time 2, for respondents without informal ACP at Time 1. Only number of chronic conditions was significantly associated with the outcome, with each chronic condition increasing the odds of informal planning at Time 2 by about 30%.

Multivariate Models: Changes in Health as a Predictor of Time 2 ACP for Respondents with no Time 1 ACP

Formal ACP

The two right-most columns of Table 6 report expanded models that add measures of change in health between Time 1 and Time 2. I hypothesized that changes in health between Time 1 and Time 2 would be associated with both forms of ACP. Contrary to the hypothesis, none of the measure of changes in health were associated

with formal ACP for people who lack ACP at Time 1. Moreover, the likelihood ratio test between the full and partial models, with four degrees of freedom representing the change in the number of parameters, is not significant, confirming that including measure of changes in health fails to improve the predictive power of the model.

Informal ACP

In the full model predicting informal ACP, only change in self-rated health in significantly related to the outcome; a one-point poorer rating of one's health increases the odds of informal ACP at Time 2 by about 30%. The likelihood ratio test between the full and partial models is significant (likelihood ratio test, $P(\chi_4^2>10.459)=.033$), indicating that full model that includes change in health variables is significantly better at predicting informal ACP at Time 2 than the smaller model that included Time 1 health measures only.

Discussion

Study 1 focused on five measures of respondent health hypothesized to be associated with the likelihood of formal and informal ACP at Time 1. These hypotheses were largely confirmed. Self-rated health was associated with both formal and informal ACP. Chronic diagnoses and major health events predicted informal ACP only, with an additional non-significant trend of association between major health events and formal ACP (p=.064). Associations were in the expected direction for chronic diagnoses and major health events; for these predictors, poorer health increased the likelihood of end-of-life planning. For self-rated health, however, poorer self-rated health slightly but significantly *decreased* the odds of both formal and

informal ACP. This is similar to a trend found by Carr and Khodyakov (2007), who found a directionally similar but with non- to marginally-significant associations where fair or poor self-rated health appears to decrease the odds of having a living will or durable power of attorney for health care.

Study 2 tested associations of Time 1 health measures and changes in health measures with the likelihood of engaging in formal or informal ACP by Time 2, for respondents who had not made plans at Time 1. Contrary to the hypotheses, Time 1 health status and changes in health status between Time 1 and Time 2 had a relatively minor influence on the likelihood of a respondent without Time 1 ACP going on to do planning by Time 2. For example, only HRQOL predicted formal ACP at Time 2, and only chronic conditions and declining self-rated health predicted informal ACP at Time 2.

The factors that appear to most affect the likelihood of formal ACP at Time 2 for respondents without formal end-of-life plans at Time 1 are not health-related. Rather, respondents who reported informal ACP at Time 1 or who were widowed since Time 1 were twice as likely to report formal ACP than other respondents. Respondents who were already widows/widowers at Time 1, however, were only half as likely to put in place formal ACP by Time 2 than their married counterparts. With regard to informal ACP, becoming a widow and greater willingness to think about death predicts a greater likelihood of reporting informal ACP at Time 2.

This analysis demonstrates the salience of diverse dimensions of individual health on the likelihood of ACP, suggesting that health states and health events are effective cues to action for ACP. Although nearly all measures of health were related

to both forms of ACP in the full Time 1 sample, this was not the case when examining individuals without ACP at Time 1. For those individuals who reported not having formal ACP when they were approximately age 64, widowhood, both recent and long-standing, and Time 1 informal ACP were the strongest predictors of whether or not they would go on to complete formal ACP by Time 2.

The choice to model formal and informal ACP as separate but related outcomes is justified by the pattern of findings. These two outcomes share many predictors, but there are also important differences, such as the relationship between HRQOL with formal ACP only, in contrast to the relationship between chronic conditions and informal ACP only. Results also show that the outcomes influence each other, although the relationship is not symmetrical; having informal ACP more than doubled the likelihood of formal ACP, but formal ACP was not a significant predictor of Time 2 informal ACP. As proposed by Carr and Khodyakov (2007), this pattern of results suggests that informal ACP may be a pathway through which individuals get to formal ACP.

The measure of self-rated health was unexpectedly associated with reduced likelihood of both types of ACP for all respondents at Time 1, but decline in self-rated health since Time 1 significantly increased the likelihood of informal but not formal ACP by Time 2 for respondents with no formal ACP at Time 1. This pattern of findings may indicate that point-in-time self-rated health is less reliable or less meaningful than relative change over time in older adults, in the context of ACP.

Study 2 focused on respondents with no ACP at Time 1 because these individuals are prime candidates for interventions to encourage ACP. Results suggest

that changes in health measures over time are not as influential on the likelihood of ACP as an individual's health status at Time 1, with the healthiest individuals (those free of chronic diseases and with high levels of HRQOL) the least likely to complete ACP by Time 2.

Limitations

The study has several limitations. First, although the study population is representative of a broad segment of the U.S. population (i.e. non-Hispanic Whites with a high school education or more), findings do not shed light on patterns of ACP among racial and ethnic minorities, an area of priority in the study of ACP (Carr, 2011; Crawley, 2005). Further, although no significant relationship has been found between state of residence and ACP activities (Carr & Khodyakov, 2007), the fact that nearly two-thirds of WLS respondents continue to reside in Wisconsin may limit the generalizability of the findings to other geographic areas, either because of latent cultural features or regional norms in the state, or because of formal policies or interventions that may effect residents of that state (see, for example, Moorman et al., 2012).

Second, the measures I used to operationalize the different domains of health were limited by what was available in the dataset. For example, the single-item measure of self-rated health is limited by how individuals interpret the question, the frame of reference used to answer it, and the health domains for which it can be considered a proxy (Bailis, Segall, & Chipperfield, 2003; Jylhä, 2009; Krause & Jay, 1994; Kempen, Miedema, van den Bos, & Ormel, 1998). Limitations of this measure may explain the different in direction of association between self-rated health and

ACP in Study 1 and Study 2. The measures of chronic conditions and major health events assessed captured some of the most prevalent conditions and events, but by no means all potentially meaningful conditions or events. In addition, for the Time 1 measures of health, I do not distinguish between past and more recent health events or diagnoses.

Finally, the portion of the analysis that seeks to identify triggers to ACP focuses on respondents who did not have any ACP in place at Time 1, when they were approximately 64 years old. Unlike truly prospective longitudinal data that would begin following individuals pre-ACP, limitations of the dataset compel this analysis to focus on people who did not have formal or informal ACP in place at age 64, unlike 60% and 74% of their peers, respectively. Consequently, findings about triggers of ACP may not be generalizable to people who proactively, and perhaps because of different triggers, made early plans for end-of-life care. However, this limitation of the dataset also lends external validity to the findings. Interventions to increase ACP are targeted at individuals like the ones in the sample, who did not have ACP in place when many of their peers did. It is possible that respondents in this analysis were especially resistant to ACP. If so, understanding the events that may make them susceptible to messages about ACP or more likely to accept support in completing ACP could inform effective interventions.

Despite limitations of the dataset and measures, results partially confirm the hypothesis that specific measures of health and changes in health are associated with ACP outcomes above and beyond the typical health and sociodemographic measures used in the literature. Healthcare providers and family members should initiate

conversations about ACP with those healthy older adults who may seem least likely to need ACP, specifically because they are the least likely to engage in end-of-life health care planning. Future research should also explore what aspects of the illness experience are causing individuals to engage in formal and informal ACP, with special focus on thorough and current planning for people with and without ACPs.

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Table 1a. Respondents by Time 1 ACP Type and Status

	Time 1 ACP Type and Status									
	Formal ACP (n=2971)		No Formal ACP (n=1972)			Informal ACP (n=3647)		No Informal ACP (n=1314)		
	# or M	% or SD	# or M	% or SD	sig.	# or M	% or SD	# or M	% or SD	sig.
Female	1585	53.3%	1080	54.8%	.327	2051	56.2%	628	47.8%	.000
Age	64.34	.69	64.33	.69	.475	64.32	.67	64.38	.72	.006
Education (yrs)	13.86	2.38	13.49	2.19	.000	13.82	2.36	13.43	2.16	.000
Marital Status					.000					.000
Married	2368	79.7%	1515	76.9%		2938	80.6%	957	73.0%	
Divorced or Separated	254	8.6%	239	12.1%		322	8.8%	176	13.4%	
Widowed	255	8.6%	129	6.5%		289	7.9%	96	7.3%	
Never Married	93	3.1%	87	4.4%		98	2.7%	82	6.3%	
Number of children	3.03	1.65	3.10	1.84	.158	3.08	1.68	2.99	1.85	.122
Conscientiousness (1-6)	4.83	.68	4.72	.69	.000	4.82	.68	4.71	.69	.000
Death avoidance	4.02	1.38	3.79	1.37	.000	4.07	1.35	3.54	1.38	.000
Physician control beliefs	3.56	1.19	3.47	1.12	.017	3.60	1.16	3.31	1.15	.000
Health										
Hospitalized in past 12 months	352	13.4%	153	9.1%	.000	399	12.4%	110	10.0%	.030
Self-rated health	2.19	.99	2.26	.98	.022	2.21	.99	2.27	.97	.087
Health Utility Index	.84	.199	.85	.19	.454	.84	.19	.85	.19	.083
Chronic diagnoses (0-3)	1.18	.84	1.18	.85	.991	1.19	.84	1.12	.86	.005
Hypertension	1408	47.5%	926	47.1%	.782	1738	47.7%	605	46.1%	.313
Diabetes	369	12.4%	250	12.7%	.792	463	12.7%	155	11.8%	.414
Joint pain, stiffness, or swelling	1712	57.6%	1139	57.8%	.936	2154	59.1%	708	53.9%	.001
Major health event by T1	.30	.53	.26	.50	.006	.30	.53	.2422	.49	.000
Cancer	366	12.3%	154	7.8%	.000	427	11.7%	97	7.4%	.000
Heart problems	451	15.2%	305	15.5%	.778	566	15.5%	191	14.5%	.391
Stroke	85	2.9%	54	2.7%	.796	107	2.9%	33	2.5%	.433
Informal ACP Time 1	2602	87.6%	1032	52.4%	.000					
Formal ACP (all types) Time 1						2602	71.6%	368	28.2%	.000
Legal arrangements such as DPAHC	2576	86.9%	0	0.0%	.000	2324	64.1%	251	19.2%	.000
Living will or advance directive	2698	91.2%	0	0.0%	.000	2402	66.3%	295	22.6%	.000

Table 1b. Respondents who reported no ACP at Time 1 by Time 2 ACP type and status

Respondents who reported no ACP at Time 1										
	Formal ACP Time 2		No Formal ACP Time 2			Informal ACP Time 2		No Informal ACP T2		
	# or M	% or SD	# or M	% or SD	sig.	# or M	% or SD	# or M	% or SD	sig.
Female	445	56.8%	371	51.2%	.030	258	47.6%	201	45.4%	.485
Age	64.33	.69	64.30	.69	.469	64.27	.69	64.46	.75	.000
Education (yrs)	13.66	2.28	13.56	2.26	.383	13.68	2.30	13.37	2.17	.031
Marital Status					.263					.553
Married	616	78.8%	549	75.9%		406	75.3%	316	71.3%	
Divorced or Separated	95	12.1%	89	12.3%		70	13.0%	67	15.1%	
Widowed	43	5.5%	58	8.0%		36	6.7%	36	8.1%	
Never Married	28	3.6%	27	3.7%		27	5.0%	24	5.4%	
Number of Children	3.13	1.84	3.19	1.83	.461	3.05	1.77	3.02	1.89	.804
Conscientiousness	4.74	.67	4.74	.69	.971	-.07	.22	-.07	.20	.964
Death avoidance	3.88	1.36	3.77	1.37	.149	3.75	1.33	3.37	1.39	.000
Physician control beliefs	3.52	1.11	3.52	1.09	.960	3.44	1.11	3.27	1.13	.031
Widowed T1 to T2	61	7.8%	26	3.6%	.000	33	6.1%	26	5.9%	.885
Parental Death T1 to T2	151	19.3%	123	17.0%	.248	106	19.6%	84	19.0%	.814
Health										
Hospitalized in past 12 mo	61	8.8%	55	8.8%	.996	59	12.4%	31	8.2%	.044
Self-rated health	2.24	.96	2.18	.94	.288	2.25	.96	2.19	.95	.381
Health Utility Index	.84	.19	.86	.18	.081	.85	.18	.85	.19	.912
Chronic diagnoses (0-3)	1.19	.83	1.16	.87	.515	1.19	.84	1.02	.84	.003
Hypertension	373	47.7%	327	45.3%	.350	249	46.0%	191	43.2%	.378
Diabetes	94	12.0%	96	13.3%	.475	68	12.6%	42	9.5%	.119
Joint pain, stiffness, or swelling	466	59.5%	419	57.9%	.518	325	60.0%	219	49.4%	.001
Major health event by T1	.27	.49	.24	.49	.320	.26	.49	.20	.48	.093
Cancer	59	7.5%	51	7.1%	.715	33	6.1%	32	7.2%	.475
Heart problems	130	16.6%	102	14.1%	.170	94	17.3%	44	9.9%	.001
Stroke	18	2.3%	20	2.8%	.566	12	2.2%	14	3.2%	.362
Change in Self-rated Health T1 to T2	.19	.92	.21	.86	.766	.23	.92	.13	.91	.087
Change in Health Utility Index T1 to T2	-.07	.22	-.07	.20	.964	-.06	.22	-.06	.20	.750

Change in chronic dx T1 to T2	.31	.73	.30	.73	.941	.31	.74	.29	.70	.747
Major health event since T1	.19	.49	.18	.49	.823	.20	.51	.16	.47	.174
Informal ACP T1	482	61.6%	323	44.6%	.000					
Formal ACP (any type) T1						168	31.30%	106	24%	0.011
Legal arrangements such as DPAHC						118	22.0%	62	14.0%	.001
Living will or advance directive						139	25.8%	85	19.4%	.017

Table 2: Results of logistic regression equations testing hypotheses

	Study 1		Study 2 (Partial Models)		Study 2 (Full Models)	
	FACP	IACP	FACP	IACP	FACP	IACP
Sex	0.923	1.362***	1.133	1.122	1.14	1.196
Age	1.094^	0.974	1.089	0.709**	1.087	0.713**
Education	1.065***	1.061**	1.029	1.026	1.029	1.04
Marital Status T1	0	0	0	0	0	
Sep/Divorced	0.678**	0.587***	0.826	0.822	0.828	0.842
Widowed	1.311*	0.979	0.514*	0.7	0.517*	0.684
Never Married	0.639*	0.37***	1.033	1.082	1.044	1.075
Number of children	0.963^	0.976	0.993	1.035	0.994	1.036
Conscientiousness	1.271***	1.21**	0.988	0.962	0.995	0.992
Death avoidance	1.123***	1.265***	1.026	1.154*	1.028	1.162*
Physician control beliefs	1.01	1.119**	0.929	1.123	0.928	1.139^
Hospitalized last 12 mo	1.636***	1.371*	1.1	1.732^	1.095	1.764^
Self-rated health T1	0.898*	0.897*	0.933	0.879	0.927	1.027
Health Utility Index	0.761	0.653^	0.41*	0.707	0.394*	1
Chronic Diagnoses T1	1.033	1.188**	0.957	1.288*	0.966	1.344*
Major Health Events T1	1.143^	1.204*	1.245	1.18	1.264	1.203
Formal ACP T1				1.245		1.285
Informal ACP T1			2.137***		2.127***	
Was Widowed			2.304**	1.247	2.326**	1.263
Parental Death			1.216	1.386	1.225	1.382
Change Self-rated health					1.001	1.324*
Change Health Utility Index					0.943	1.484
Change Chronic diagnoses					1.037	1.197
Change Major Health Event					1.092	1.124
Constant	0.001*	1.169	0.006	1656436858.271**	0.006	341219370.105*
-2 LL	5023.977	4112.386a	1419.344a	887.949a	1418.660a	877.490a
Cox & Snell R Square	.034	.056	.056	.056	.056	.071

Nagelkerke R Square	.046	.084	.074	.076	.075	.095

*<.05, **<.01, ***<.001, ^<.10

Figure 1. Respondents by ACP status at Time 1, with reasons for missing respondents at Time 2

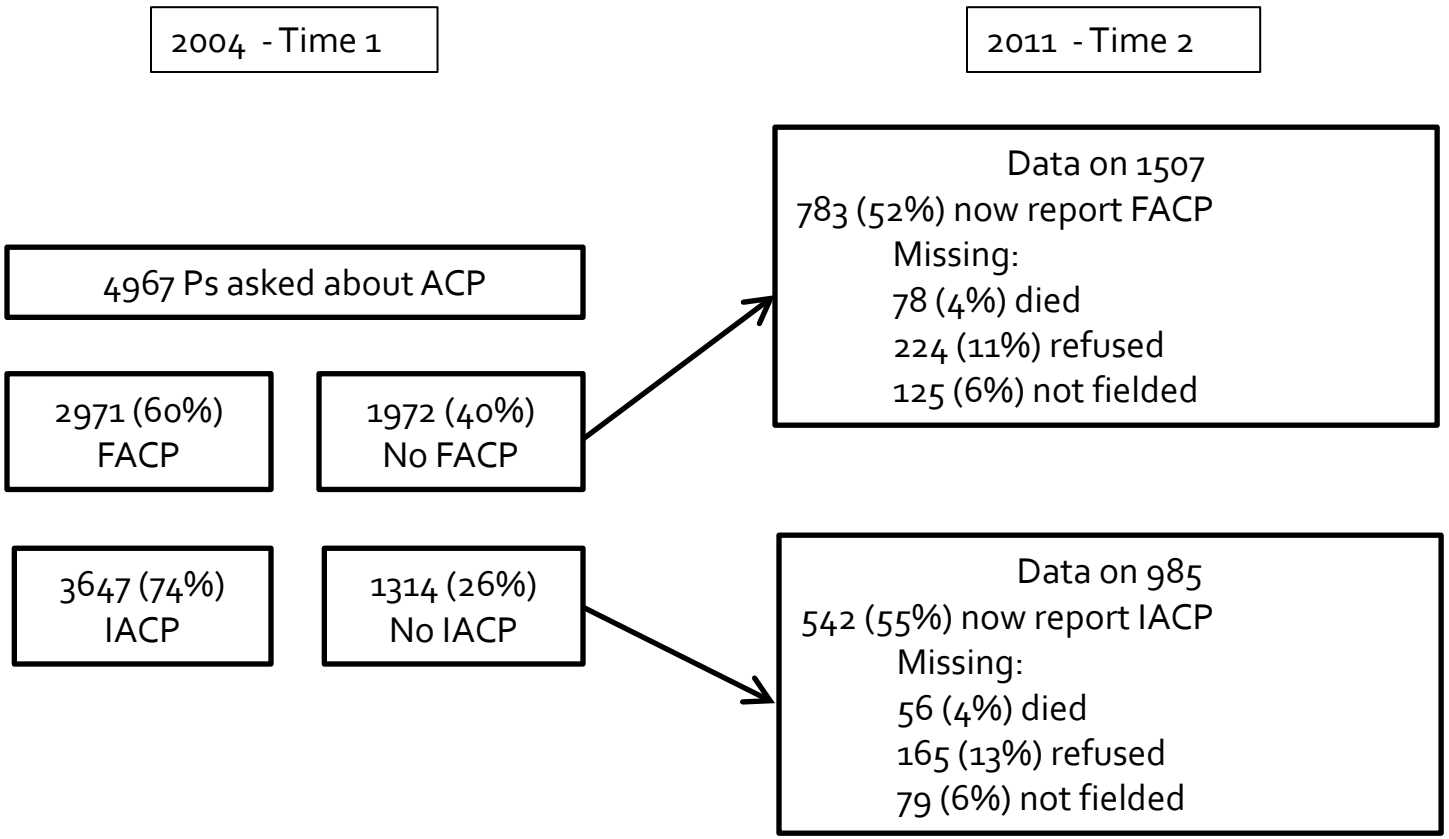
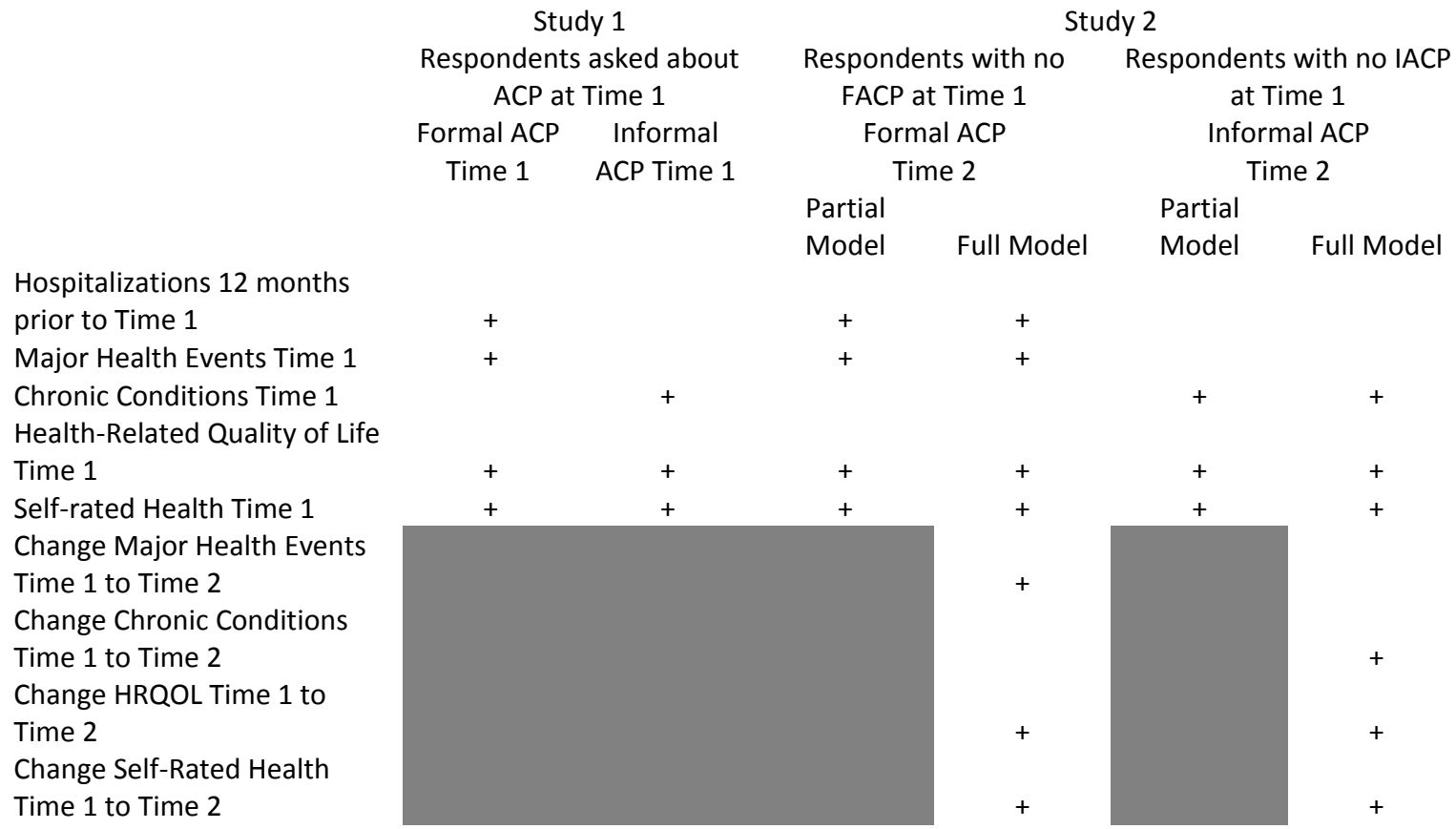


Figure 2. Hypothesized relationship between health measures and outcomes.



CHAPTER 3

SOCIAL DIFFUSION OF ADVANCE CARE PLANNING AMONG RELATED OLDER ADULTS

Abstract

Objectives: To apply concepts of social diffusion of health behaviors (Smith & Christakis, 2008) to advance care planning (ACP) by examining (1) the extent to which formal (legal) and informal (discussions of wishes) advance care planning (ACP) status is shared between older adult married couples and siblings, (2) the cross-section association of sibling and spouse ACP status on the planning status of the focal individual, when controlling for other factors related to ACP, and (3) the effect of sibling and spouse ACP status on the likelihood that a focal individual without ACP at baseline would complete ACP by a follow-up interview seven years later.

Methods: This study uses the 2004 and 2011 waves of the Wisconsin Longitudinal Study. Logistic regression equations were run to assess the association of sibling and spouse ACP status with the ACP status of the focal individual at Time 1, and the effect of sibling and spouse ACP status at Time 1 on focal individual's ACP status at Time 2, for focal individuals who did not have ACP at Time 1. All models control for the health and sociodemographic characteristics of the focal individual, known predictors of ACP. Based on the theory and previous research on social diffusion of health behaviors, planned interactions test how closeness with spouse and contact, closeness, and common gender between siblings may affect the influence of others' ACP status on the focal individual. Additional planned interactions test for a compounding effect of important others' status (i.e. additional likelihood of planning if both spouse and sibling have ACP).

Results: In the adjusted model predicting Time 1 planning, spouse formal and informal ACP is associated with the focal individual's formal ACP at Time 1, and spouse

formal and informal, and sibling informal ACP are associated with the focal individual's informal ACP. No interactions were significant in the cross-sectional model. When predicting Time 2 ACP for focal respondents without formal or informal ACP at Time 1, spouse and sibling formal ACP and an interaction term for spouse x sibling formal ACP effect the focal individual's likelihood of formal ACP at Time 2; both spouse and sibling formal ACP increased the odds of a focus individual engaging in formal ACP, but the effect is dampened if both spouse and sibling have formal ACP. Neither type of spouse and sibling planning affected the focal individual's likelihood of informal ACP by Time 2.

Discussion: Spouse and sibling ACP status are associated with the focal respondent's ACP status at Time 1 (cross-sectionally), indicating homophily within family networks with respect to ACP. Spouse and sibling formal ACP affects the likelihood of a respondent without formal ACP at Time 1 completing formal ACP by Time 2. However, the lack of a cumulative effective of formal ACP (i.e. additive effect of spouse and sibling formal ACP) suggests the possibility that individuals without ACP may be especially resistant to ACP or find it difficult to complete ACP when they are alone in their no-ACP status. Future research should examine the spread of ACP within social networks beyond the family, and seek to understand social diffusion of ACP in younger middle aged adults.

Introduction

Decisional incapacity is very common at the end of life (Kim, Karlawish, & Caine, 2001), with recent data suggesting that nearly 30% of older adults decedents both required and were unable to make medical decisions in the last days of life (Silveria, Kim, & Langa, 2010). In these situations, family members or other proxies are often called on to direct the health care a patient receives. Individuals can record their wishes and directions for proxies thorough legal arrangements, such as advance directives, living wills, or Durable Powers of Attorney for Health Care. Another way that patients' wishes can be made known are through discussions about wishes for end-of-life care with their family, friends, care providers, or clergy. These processes are known as formal and informal advance care planning (ACP), respectively. A combination of formal and informal ACP is increasingly recommended (Sudore & Fried, 2010) for several reasons. ACP has been shown to align the treatments patients receive with the types of treatments that they had documented a wish to receive (Silveria et al., 2010) and is associated with qualities of a "good death," such as hospice enrollment and less aggressive treatment at the end of life (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). Other benefits of ACP are conferred to survivors and to the health care system as a whole; ACP has also been shown to facilitate proxy decision-making (Braun, Beyth, Ford, & McCullough, 2008; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007), improve well-being of survivors (Detering, et al., 2010) and reduce EOL health care costs (Elsayem et al., 2004; Morrison, et al. 2008; Smith, et al., 2003).

Approximately 70% of older adults have some form of ACP in place

(Morrison & Meier, 2004; Silveria et al., 2010; Teno et al., 2007). Despite these fairly high rates, and partly because of the racial and socioeconomic disparities in rates of ACP (Carr 2012b; Carr 2012c; Kwak & Haley, 2005), increasing the rate of ACP completion remains a public health goal (Field & Cassel, 1997; Morhaim & Pollack, 2013).

Most research on ACP has focused on the individual and interpersonal factors that correlate with planning, such as gender, education, marital status, and experience with others' death and dying. For example, female gender, White race, more years of education, more advanced age, being married, and poor health have all been positively associated with ACP (Black, Reynolds, & Osman, 2008; Bravo, Dubois, & Pâquet, 2003; Carr & Khodyakov, 2007; Carr, 2012a; Carr 2012b; Hopp, 2000; Kahana, Dan, Kahana, & Kercher, 2004; Kwak & Haley, 2005). Another strand of research has focused on how stressful life events affect the likelihood of planning. Research on these events shows that events like hospitalization, a difficult or painful death of a spouse or parent (Carr, 2012a; Carr & Khodyakov, 2007), and the presence or recent diagnosis of a medical condition for oneself or a friend or relative (Pollack, Morhaim, & Williams, 2010) all increase the likelihood of ACP.

Unlike the dominant epidemiological or coping-based explanations of ACP, a third conceptual approach to ACP has been to consider end-of-life health care planning a preventative health behavior (Fried, Bullock, Iannone, & O'Leary, 2009; Carr, 2012c), that is, something that relatively healthy people do to prevent poor health or healthcare experiences in the future (Kasl & Cobb, 1966). There are many theories of how and why individuals engage in health behaviors, but a recent theory

that has been applied to health behaviors with much interest is social diffusion; that is, the ideas that health behaviors of family and friends have a significant impact on the health behaviors of individuals (Smith & Christakis, 2008). I propose that the personal and private nature of end-of-life discussions makes ACP a likely phenomenon to spread within and be influenced by family members' ACP status. Shared family culture and other exogenous shared experience, like the death of a family member, would also affect family members in similar ways. Despite the strong evidence for social diffusion influencing health behaviors like obesity, smoking, alcohol use, and mammography (Christakis & Fowler, 2007; Christakis & Fowler, 2008; Murabito et al, 2001; Rosenquist, Murabito, Fowler, & Christakis, 2010), theory of social diffusion has only begun to be applied to ACP (i.e. Moorman, Carr, Kirchhoff, & Hammes, 2012). Therefore, to extend the current understanding of ACP, this research investigates the applicability of social diffusion of ACP between spouses and siblings in the Wisconsin Longitudinal Study.

Social Diffusion of Health Behaviors

Evidence of social diffusion of health within families can be found at several levels of relationships and contact, with many possible mechanisms offered as explanation of the effects (Berkman, Glass, Brissette, & Seeman, 2000; Lewis et al., 2006). For example, the health benefits of marriage (Kiecolt-Glaser & Newton, 2001; Rendall, Weden, Favreault, & Waldron, 2011) are partly attributable to social support, social control, enhanced joint motivation to adopt risk-reducing health behaviors, and biological effects (i.e. physiological effects of social support and stress; Lewis et al.,

2006; Rendall et al., 2011; Robles & Kiecolt-Glaser, 2003). Research has shown that siblings may share health states and health behaviors as a result of both shared genetic heritage and environment. In adolescents, attitudes about alcohol use and risky sexual behaviors are transmitted from older to younger siblings (D'Amico & Fromme, 1997). Beyond any genetic risk factors, studies of adolescent twins and siblings have found social contagion of smoking and alcohol use between siblings, moderated by social connectedness, as measured by sibling contact and mutual friendships (Rende, Slomkowski, Lloyd-Richardson, & Niaura, 2005; Slomkowski, Rend, Novak, Lloyd-Richardson, & Niaura, 2004). Even more distant family ties than siblingship have been linked to rates of mammography screening for breast cancer, which were found to be higher in women with a family history of breast cancer, regardless of their perception of personal risk of breast cancer (Murabito et al., 2001). This finding speaks to the significant role of family networks in health behaviors, which remains even after other important predictors are controlled.

Health behaviors travel within but also beyond family networks. In studies utilizing the Framingham Heart Study, Christakis and Fowler (2007, 2008) found that the more smoking (and smoking cessation) and obesity spread through an individual's entire social network, including family members, friends, and friends of friends. A more recent study of alcohol use in the same dataset had largely similar findings (Rosenquist et al., 2010). Several findings in these studies suggest general principles of social influence that may hold true for other health behaviors. First, the spread of both obesity and alcohol use was moderated by gender. For example, in the case of obesity, a sibling or friend of the same gender more likely to influence the focal

individual than a sibling or friend of the same gender. Second, in all three cases of smoking, obesity, and alcohol use, influence among associates was not affected by the geographic distance between individuals, suggesting that physical contact is not crucial to the diffusion of behaviors. Finally, in the study of alcohol use, there was an additive effect of having multiple heavy drinkers or abstainers in one's network; the odds of a focal individual becoming a heavy drinker or abstainer was related to the proportion of contacts in his or her network that engaged in these behaviors.

The robust literature on familial and social transmission of health behaviors motivates the topic of the current research, namely, how does the ACP status of a spouse or sibling affect an individual's likelihood of planning? Only one study has investigated the social diffusion of ACP (but see Clarke, Evans, Shook, and Johanson (2005) for an example of an attempt to use social networks to promote ACP). Moorman and colleagues (2013) tested the possibility of social diffusion of the effects of a regional, multi-component public health intervention to encourage ACP in La Crosse, Wisconsin, that began in 1991. They found no evidence of social diffusion of ACP. On the contrary, respondents who were exposed to the intervention were less likely to have completed formal ACP than respondents with no exposure.

The perceived effectiveness of peer education or small group models for ACP (Seymour, Almack, Kennedy, & Froggatt, 2011) may be congruent with Moorman and colleagues' (2013) results for one of the reasons they suggest for their findings. Unlike diet, exercise, or smoking, ACP is not a public or highly visible behavior. Rather, ACP largely involves private conversations between family and friends, with health care providers, and/or with legal counsel. Pre-existing similarity between spouses and

siblings (i.e. homophily (McPherson, Smith-Lovin, & Cook, 2001)) in their attitudes (e.g. cultural norms about discussing death, views on patient autonomy) and experience with the death of close others would support the likelihood that family members are both likely partners for talking about ACP and likely influences on an individual's likelihood of ACP. Social diffusion of ACP may therefore be restricted to family or other intimate networks, the individuals who would be more likely to be having conversations on the topic, and not readily promoted through broad social marketing campaigns, like the one described by Moorman and colleagues.

In this chapter, I test hypotheses about the association of spouse and sibling ACP status with the ACP status of a focal individual and how ACP may diffuse through families over time. Study 1 focuses on cross-sectional associations, testing the hypothesis that spouse and sibling ACP status at Time 1 will be positively associated with respondent ACP at Time 1. Study 2 focuses on respondents without ACP at Time 1, and tests the hypothesis that spouse and sibling ACP status at Time 1 will predict respondent ACP status at Time 2.

Methods

Data

This analysis uses two recent waves of the Wisconsin Longitudinal Study (WLS), a study that has followed 10,317 individuals who graduated from Wisconsin high schools in 1957 ("graduates"). Two features of this dataset make it suitable for testing my hypotheses. First, the WLS has expanded its sample from graduates only to (when possible) the spouses of graduates and a randomly selected sibling of each

graduate. (Hereafter, *graduate* refers to the focal individual, whose ACP status is the dependent variable, *spouse* refers to the graduate's spouse at Time 1, and *sibling* refers to the randomly selected sibling, chosen by the WLS for inclusion in the survey beginning in 1977.) Second, the 2004-2006 wave of data collection (that surveyed graduates, spouses, and selected siblings) and the 2011 wave (that surveyed graduates) asked a series of questions about end-of-life preparations. Knowing each graduate's family context of ACP (i.e. ACP status of spouse and selected sibling) and being able to follow individuals over time makes it possible to test the cross-sectional associations of family members' ACP status on the graduate's ACP status, and, for graduates without ACP at Time 1, the influence of family members' ACP status on the likelihood of later planning.

Formal and Informal Advance Care Planning - separate but related outcomes

Formal and informal ACP -- the outcomes of interest in this study – are derived from three questions asked in the WLS. In 2004, a 70% random sample of respondents was asked about ACP. In 2011, all respondents were asked. The module was introduced with: "Now I am going to ask you some questions about the later years in life. Have you made plans about the types of medical treatment you want or don't want if you become seriously ill in the future?" Participants were then asked: 1) Have you discussed your health care plans and preferences with anyone?", "2) Have you made any legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? (This is sometimes called a Durable Power of Attorney for Health Care)", and "3) Do you have a living will or an

advance directive? (This is written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate?)." For the purposes of this study, a respondent has made informal ACPs if he or she reports having discussed health care plans and preferences with anyone. The measure of formal ACP corresponds to a participant either having made legal arrangements *or* having written instructions.

Formal and informal ACP are often completed concurrently, and each has been shown to affect the likelihood of completing the other (Carr & Khodyakov, 2007). Therefore, I include an indicator of formal or informal ACP at Time 1 in the models that predict the other type of planning at Time 2.

Controls for factors associated with ACP

Sex, age, education, marital status, number of children, and race have all been found to be associated with ACP (Black, Reynolds, & Osman, 2008; Bravo, Dubois, & Pâquet, 2003; Carr & Khodyakov, 2007; Carr, 2012a; Carr 2012b; Hopp, 2000; Kahana, Dan, Kahana, & Kercher, 2004; Kwak & Haley, 2005). I adjust all models for these factors (sex (male is reference); education and age in years; marital status as four categories with married as reference; number of children), with the exception of race, because the WLS is nearly exclusively White (<.5% non-White).

I also control for the influence of personality (conscientiousness) and attitudes (death avoidance and physician control beliefs) that have been shown to be related to ACP (Carr & Khodyakov, 2007). Conscientiousness was measured with 6 items. A representative question was, "To what extent do you see yourself as someone who

does a thorough job?" I averaged these items to a single item, ranging from 1 to 6, where higher values correspond to higher levels of conscientiousness. Missing values for respondents with 1 to 3 missing respondents were imputed to the mean of valid items. Death avoidance was measured with a single question "To what extent do you agree that you avoid thinking about death altogether?" (1=Agree Strongly to 6=Disagree Strongly), with higher score reflecting a greater willingness to think about death. Higher scores (range 1 to 6) indicate a stronger endorsement of patient (versus physician) control in medical decisions based on the question, "To what extent do you agree that you would rather have your doctor make the decisions about what's best for your health than to be given a whole lot of choices?"

Recent life events have also been associated with ACP. Hospitalizations in the previous year, having a spouse or parent experience a painful or difficult death (Carr, 2012a; Carr & Khodyakov, 2007), and the presence or recent diagnosis of a medical condition for oneself or a friend or relative (Pollack, Morhaim, & Williams, 2010) are all associated with an increased likelihood of ACP. I include an indicator for having spent at least one night in the hospital as a patient in the last 12 months, reported at Time 1. I also include an indicator of having been widowed between Time 1 and Time 2 (respondents who reported any status other than widow/er at Time 1 and a marital status of widow/er at Time 2). Being widowed between Time 1 and Time 2 is included as a control when testing for what factors trigger ACP for respondents without ACP at Time 1 for two reasons. First, the primary change in marital status in this sample between the two time points was being widowed, representing about 80% of changes in marital status. Second, others' deaths, including both the poor-quality death of a

spouse or parent (Carr & Khodyakov, 2007) as well as "good deaths" that were at home and free from pain (Carr, 2012), are associated with ACP.

The models include four measures related to different aspects of respondent health at Time 1. *Self-rated health*, a measure of perceived health, was solicited from all respondents by asking "In general, would you say your health is: excellent, very good, good, fair, or poor?" (1=excellent, 5=poor). I represent *health related quality of life* with the Health Utility Index Mark 3 (HUI3; Horsman, Furlong, Feeny, & Torrance, 2003). The HUI3 evaluates six domains (vision, hearing, speech, mobility, dexterity, emotions, cognition, and pain) with five or six questions that ask about abilities or mental state in the past four weeks to determine domain-specific scores. For example, "During the past 4 weeks, has Participant been able to see well enough to read ordinary newsprint without glasses or contact lenses?" Subsequent questions ask about the ability to read with glasses, to recognize a friend at a distance with and without glasses, and to see at all. Scores in each of the domains are combined into a continuous score ranging from 0 to 1 where 0 is a state of health equivalent to death and 1 is perfect health.

The presence of up to three *chronic conditions* assessed in the WLS were counted: high blood pressure or hypertension; diabetes; or pain, stiffness, or swelling in the joints. These conditions are an appropriate measure of chronic conditions because, in contrast to major health events, they are common but often manageable with low to moderate levels of symptom burden.

Following Moorman and colleagues (Moorman & Carr, 2008; Moorman, Carr, Kirchhoff, & Hammes, 2012), a measure of *major health events* was created based on

whether or not the respondent reported a doctor diagnosis of heart problems, stroke, or cancer ("cancer or a malignant tumor, not including minor skin cancers"). This measure ranges from 0 to 3.

Finally, I control for reported closeness (1=Not at all close to 4=Very close) between the graduate and his or her spouse and sibling as a proxy for relationship quality, a factor that has been found to be related to knowledge of a partner's end-of-life wishes (Moorman & Carr, 2008), and frequency of contact with the selected sibling in the past year, a plausible pathway for diffusion of ACP status. Frequency of contact was grouped into eight levels of past 12 month contact frequency: never, once, twice, several times (3-5), every few months (6-11 times), monthly or bi-weekly (12-23 times), twice a month to weekly, and weekly or more often. Based on Christakis and Fowler's (2008) findings that geographic distance does not modify the transmission of smoking behaviors, I do not differentiate between phone or in-person contact.

Analysis plan

To understand the joint effects of spouses and siblings, I use only complete triads of graduate, spouse, and sibling, which limits the sample to married graduates with siblings, all of who responded to the survey. Study 1 tests the cross-sectional association of family members' ACP status (i.e. planning status of spouse and sibling) on the graduate's ACP status by estimating two binary logistic regressions predicting Time 1 formal and informal ACP status, respectively, controlling for the aspects of demographics, attitudes, and health described above. The independent variables are

spouse and sibling formal and informal ACP at Time 1. The overall hypothesis to be tested is that spouse and sibling ACP status will be associated with the ACP status of the graduate.

A second study tests the effect of family members' ACP status on the graduate's ACP status at Time 2, for graduates without ACP at Time 1. In Study 2, I estimate binary logistic regressions with graduates' Time 2 formal and informal ACP as the outcome, controlling for demographics, attitudes, health, and also recent death of spouse and parents, all known predictors of ACP. The independent variables are spouse and sibling formal and informal ACP at Time 1. As above, the general hypothesis to be tested is that spouse and sibling ACP at Time 1 is related to graduate ACP status at Time 1.

Previous research and theory suggest that social diffusion may be moderated by gender concordance, relationship quality, and proportion of social network engaged in a given health behavior (Christakis & Fowler, 2007; Christakis & Fowler, 2008; Rende et al., 2005; Rosenquist et al., 2010; Slomkowski et al., 2004). In order to explore these possibilities for ACP, planned interactions will explore the effects of gender (sibling sex by sibling ACP status), closeness (spouse ACP by closeness with spouse, sibling ACP by closeness with sibling), contact (sibling ACP by contact with sibling), and the additive effects of spouse and sibling ACP status (spouse ACP by sibling ACP). Regarding interactions, no specific hypotheses are proposed because it is unclear that the same patterns of moderation or conditionality present for other health behaviors and within social networks will be found for ACP in particular and within family networks.

Results

Sample Description

There were 1378 graduates in complete triads (i.e. married to a respondent spouse who was in the ACP subsample, with a respondent sibling who was also in the ACP subsample) who were asked questions about ACP at Time 1 (2004; see Table 1). Less than half of these graduates were female (45%), with an average age of 64 years and mean 14 years of education. On average, graduates had 3.2 children, and reported high closeness with spouses and lower closeness with siblings (M=3.82 and M=1.88 respectively, on a scale of 1 to 4). Most graduates had fairly frequent contact with the selected sibling, with about 65% of graduates reporting at least monthly contact, and a quarter reporting weekly or more frequent contact. Most graduates reported good health (M=2.08) and health related quality of life (HUI M=.86), with chronic conditions the most common health problem, with an average of just over one chronic condition reported by graduates. Hospitalizations in the past 12 months and major health events were relatively infrequent but not rare, with nearly 11% of respondents reporting having spent a night in the hospital in the past year and almost 30% reporting having had a stroke, heart attack, or cancer diagnosis.

Overall, 63% and 77% of graduates reported formal and informal ACP at Time 1, respectively. This pattern was similar in spouses and siblings, with 65% and 75% of spouses and 62% and 73% of siblings reporting formal and informal ACP. At Time 2, of the graduates without each type of planning at Time 1, 55% and 57% had gone on to report formal and informal ACP by Time 2 (see Figure 1).

Bivariate Results

This research focuses on how spouse and sibling ACP status affect the graduate's ACP status cross-sectionally (Study 1) and over time (Study 2). However, graduates who chose to engage in ACP differ from those who do not on several important dimensions (see Table 2). At Time 1, graduates with formal ACP had more education, fewer children, reported greater closeness to spouse, lower death avoidance, more hospitalizations, poorer self-rated health and much more likely to have informal ACP or a spouse or sibling with formal or informal ACP. Graduates who reported informal ACP at Time 1 were more likely to be female, more educated, closer to their spouse, and also more conscientious, less death avoidant, endorsed more patient (versus physician) control in medical decision-making, and much more likely to have formal ACP or a spouse or sibling with formal or informal ACP.

At Time 2 (see Table 3), graduates who went on to make formal ACP were disproportionately women and individuals with a greater willingness to talk about death, who had been widowed since Time 1, and with spouses who had formal ACP at Time 1. Graduates without informal ACP at Time 1 who went on to do informal ACP by Time 2 were more willing to think about death, desired more patient (versus physician) control, had more chronic conditions, and were more likely to have a sibling with informal ACP at Time 1.

Correlations

Moderate to strong correlations (i.e. >.3) between variables are noted in this

section. For the sample of interest in Study 1 -- graduates in complete triads who were asked about ACP at Time 1 -- several noteworthy correlations. Graduate formal and informal ACP are correlated (r=.371), as are spouse formal and informal ACP (r=.381) and sibling formal and informal ACP (r=.416). Spouse formal and informal ACP are correlated with graduate formal ACP (r's .556 and .305). Also, as might be expected, self-rated health is correlated with functional status (HUI), chronic conditions, and major health events (r's -.424, .343, and .329).

A similar pattern of correlation is present within the sample of graduates in Study 2, those without formal ACP at Time 1; self-rated health is correlated with health related quality of life, chronic conditions, and major health events (r's -.383, .337, and .359). Sibling formal and informal planning are moderately correlated (r=.430), as are graduate's informal ACP at Time 1 and Time 2 with their informal and formal ACP at Time 2, respectively (r's .327 and .430). An unexpected bivariate relationship was observed: reported closeness to the sibling was moderately and inversely correlated with the amount of reported contact with the sibling in the past 12 months (r=-.612).

For the sample of graduates without informal ACP at Time 1, the only moderate correlations were between sibling closeness and sibling contact (r=-.592), self-rated health and functional status (r=-.446), formal ACP at Time 1 and Time 2 (r=.447), and sibling formal and informal ACP (r=.442).

Study 1: Association of spouse and sibling ACP status with graduate's ACP status at Time 1

Formal ACP

Results of the two binary logistic regressions that predict graduate formal and informal ACP at Time 1 are shown in the first panel of Table 4. These models include only main effects as none of the planned interactions were significant. Net of controls, spouse formal and informal ACP were significantly associated with formal ACP status of the graduate at Time 1. Having a spouse with formal ACP resulted in over a 12-fold increase in the likelihood of the graduate having formal ACP. A spouse report of informal ACP was also significantly associated with a 1.5 times increase in the graduate's likelihood of reporting formal ACP. Neither sibling formal nor informal ACP were associated with graduate formal ACP at Time 1, although the graduate report of closeness to sibling was significant as a main effect (OR=1.339). A similar odds ratio was estimated for closeness to spouse, as well, but was marginally significant (p=.051).

Informal ACP

Spouse formal (OR=2.356, p<.001) and informal ACP (OR=2.88, p<.001), as well as sibling informal ACP (OR=1.718, p=.004) were all associated with graduate Time 1 informal ACP. Closeness to spouse (OR=1.621, p=.01) but not closeness to sibling was associated with graduate informal ACP at Time 1.

Study 2: Effect of spouse and sibling Time 1 ACP status on graduate's ACP status at Time 2, for graduates without plans at Time 1

Formal ACP

Results of the two binary logistic regressions that predict formal and informal

ACP at Time 2, for graduates without each type of planning at Time 1, are shown in the second panel of Table 4. When predicting Time 2 formal ACP, only one planned interaction was significant, the interaction of spouse formal ACP and sibling formal ACP. This interaction term was added to the model both because of the statistical significance of the parameter estimate, and because the addition of this interaction term increased model fit significantly (likelihood ratio test, $P(\chi_1^2>6.385)=.0115$). Notably, the main effects of spouse and sibling formal ACP were not statistically significant until the addition of the interaction term (OR=3.19, p=.006 and OR=1.775, p=.064, for spouse and sibling formal ACP respectively, in the final model). Both spouse and sibling FACP status have main effects in the expected direction. The interaction term, however, is not as hypothesized. Prior research on social diffusion of alcohol use in adults has found additive effects of that health behavior (Rosenquist et al., 2010). That is, a greater proportion of associates exhibiting either heavy drinking or abstinence from alcohol increases the odds of the focal individual adopting the dominant behavior. In this estimation of the likelihood of graduate formal ACP at Time 2, the odds ratio for the interaction term is less than one (OR=.258, p=.013), indicating that while having a spouse with formal ACP increases the graduates odds of planning by about 3 (i.e. 3.19=exp(1.16)), and having a sibling with formal ACP increases the odds by almost 2 (i.e. 1.775=exp(.574)), having both a spouse *and* a sibling with formal ACP would not result in an additive increase (i.e. 5.66=exp(1.16+.574)), but rather an attenuated effect on the likelihood of a graduate doing formal ACP by Time 2 (i.e. 1.46= exp(1.16+.574-1.35), the odds ratio for a graduate with both sibling and spouse reporting formal ACP at Time 1).

Informal ACP

When predicting Time 2 informal ACP, no planned interactions were significant. Moreover, none of the independent variables were significant related to the outcome of graduate informal ACP at Time 2, for graduates without informal ACP at Time 1. Similar to the cross-sectional models, there was a significant main effect of closeness to sibling at Time 1 (OR=1.911, p=.035) on the graduate's likelihood of informal ACP at Time 2, for graduates who reported no informal ACP at Time 1. As found in prior research ([Chapter 2, above]), graduates with more condition conditions were more likely to do informal ACP by Time 2 (OR=1.891 , p=.003). There was also a marginally significant of being widowed between Time 1 and Time 2, with the death of a spouse decreasing the odds that a graduate would complete informal ACP by Time 2 (OR=.245, p=.052).

Discussion

In Study 1, I found strong cross-sectional associations of spouse and sibling ACP status on graduates' formal and informal ACP at Time 1. A spouse's formal and informal ACP statuses were related to both the graduate's likelihood of formal and informal ACP. The ACP status of siblings was less strongly related, and confined to an association between sibling informal ACP and graduate informal ACP only. This pattern of results and other significant main effects highlight the social dimensions of ACP; the unanticipated main effect of spouse and sibling closeness on informal and formal ACP, respectively, suggest that relationship quality and feelings of social connectedness predispose individuals to end-of-life planning.

In the second study that tested the social diffusion of ACP between family members over time, I found no evidence for diffusion of informal ACP from either spouse or sibling to the graduate; the odds of a graduate without informal ACP at Time 1 reporting informal ACP by Time 2 was affected by other known predictors of informal ACP, like chronic conditions, attitudes about death and physician control, and being widowed, but not by the informal ACP status of his or her spouse or sibling. However, the formal ACP status of a spouse and sibling at Time 1 did increase the likelihood of a graduate without formal planning going on to complete formal ACP by Time 2. The interaction term to test for a synergistic cumulative effect of spouse and sibling formal ACP was significant, but not in the expected direction. Although prior research on social diffusion of health behaviors and intuition would lead us to expect that having both a sibling and spouse with formal ACP would have a greater effect than the additive effect of a spouse and sibling separately, the significant and negative interaction term indicate that, within this sample, having both spouse and sibling with formal ACP dilutes the diffusion effect. This effect must be interpreted within the context and limitations of the dataset, namely, that this finding is based on 71 respondents without formal ACP at Time 1 who had both a spouse and sibling with formal ACP. These 71 respondents comprise about 17% of the cases in that portion of the analysis. Despite the statistical significance of the interaction effect, Type 1 error cannot be ruled out, nor can we know that the behavior of respondents in this particular circumstance would generalize to others in this situation. However, if we accept the accuracy of the finding, the trend may echo an argument suggested by Moorman and colleagues (2013) as a reason for their non-finding of social diffusion:

psychological reactance, the tendency for people to react negatively when bombarded with a message. It is possible that having multiple people in a family with formal ACP creates an environment in which change is more difficult, perhaps because there are fewer available partners with whom to jointly engage in the process of planning. Alternately, graduates who fail to do formal ACP by Time 2 may be an especially resistant or avoidant group of people; non-planners are already in the minority at Time 1, with 60% and 75%, respectively, having formal and informal ACP in place. This suggests that individuals without ACP at Time 1 may represent an especially ACP-resistant group, and/or that social diffusion of ACP may be more accurately studied in a younger age group, over a time period in which the majority of the cohort is engaging in planning.

Limitations

This analysis is limited in several ways due to the data set. The cross-sectional analysis contained over 1300 graduates, but only 424 and 259 graduates, respectively, were without formal or informal ACP and completed the Time 2 survey. The small sample size raises the possibility that the lack of significant effects, in the case of informal ACP, is due to lack of power.

Several of the predictors were moderately to strongly correlated predictors, which introduces multicolinearity that could bias estimates. However, evaluation of alternative models that omitted correlated predictors yielded similar parameter estimates and patterns of significance.

The use of secondary data limited the set of possible predictors and controls.

For example, no information was available on the ACP status of other siblings' and the deaths of other close family members or friends, circumstances that would likely have affected the outcomes.

Finally, to quantify the joint contribution of spouse and sibling ACP status on the graduate's status, this analysis used only complete triads. The individuals who participate in longitudinal studies may be particularly conscientious or compliant people to begin with, and this trait may be magnified all the more pronounced in families in which multiple members participated (i.e. graduate, sibling, spouse). Individuals without sibling respondents and people who were not married at Time 1 are also not represented by this analysis. To the extent that the WLS may reflect a subset of the population, more research is needed in larger, more representative samples.

Conclusion

This research finds evidence that formal and informal ACP are common in respondents in general and tend to co-occur in spouse and sibling dyads. A portion of this research found that formal ACP appears to spread between spouses and siblings over time, for older adults without formal ACP. Future research on correlates and causes of ACP should incorporate ACP status of family members and friends to improve the predictive power of models. Also, interventions to promote ACP should utilize theories that take into account how social context and contact can foster health behavior change, understanding that ACP may share properties of other health behaviors to be adopted by and shared among families.

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Table 1: Means (SD) and counts (%) for graduates in complete triads who were asked and answered questions on ACP at Time 1 (n=1378)

	# or M	% or SD
Female	624	45.3%
Age	64.25	.63
Education	14.04	2.49
Number of children	3.23	1.66
Closeness to spouse	3.82	.41
Closeness to sibling	1.88	.81
Contact with Sibling in past year		
Never	38	2.8%
Once	51	3.7%
Twice	62	4.5%
3-5 times	175	12.8%
6-11 times	167	12.2%
12-23 times (monthly to bi-weekly)	314	22.9%
24-51 times (bi-weekly to weekly)	219	16.0%
Greater than 51 times (weekly or more)	343	25.1%
Conscientiousness	4.79	.69
Death avoidance	3.98	1.38
Physician control beliefs	3.57	1.15
Hospitalizations	137	10.8%
Self-rated health	2.08	.92
Health Utilities Index	.86	.18
Chronic Conditions	1.13	.81
Major Health Events	.28	.52
Graduate FACP T1	867	63.2%
Graduate IACP T1	1057	76.8%
Spouse FACP	890	65.0%
Spouse IACP	1037	75.4%

Sibling FACP	854	62.2%
Sibling IACP	1010	73.3%

Table 2: Means (SD) and counts (%) comparing grads in complete triads by ACP status at Time 1 (n=1378)

	Time 1 ACP Type and Status									
	Formal ACP (n=867)		No Formal ACP (n=504)			Informal ACP (n=1057)		No Informal ACP (n=320)		
	# or M	% or SD	# or M	% or SD	sig.	# or M	% or SD	# or M	% or SD	sig.
Female	380	43.8%	240	47.6%	.174	499	47.2%	125	39.1%	**.010**
Age	64.26	.61	64.22	.66	.275	64.23	.62	64.28	.67	.207
Education	14.28	2.54	13.64	2.35	**.000**	14.20	2.53	13.52	2.29	**.000**
Number of children	3.14	1.57	3.38	1.79	**.011**	3.19	1.64	3.36	1.72	.110
Closeness to spouse	3.84	.39	3.79	.44	**.020**	3.84	.39	3.75	.45	**.001**
Closeness to sibling	1.89	.80	1.87	.82	.569	1.87	.82	1.92	.76	.288
Contact with Sibling in past yr					.251					.133
Never	19	2.2%	19	3.8%		23	2.2%	15	4.7%	
Once	30	3.5%	21	4.2%		37	3.5%	14	4.4%	
Twice	45	5.2%	17	3.4%		52	5.0%	10	3.1%	
3-5 times	106	12.3%	68	13.6%		127	12.1%	48	15.0%	
6-11 times	100	11.6%	64	12.8%		125	11.9%	41	12.9%	
12-23 times	197	22.9%	117	23.4%		247	23.5%	67	21.0%	
24-51 times	136	15.8%	83	16.6%		168	16.0%	51	16.0%	
>51 times	229	26.6%	111	22.2%		270	25.7%	73	22.9%	
Conscientiousness	4.82	.68	4.76	.69	.166	4.82	.69	4.73	.68	**.044**
Death avoidance	4.06	1.41	3.82	1.31	**.002**	4.09	1.36	3.57	1.36	**.000**
Physician control beliefs	3.61	1.16	3.49	1.13	.062	3.65	1.15	3.32	1.11	**.000**
Hospitalizations	98	12.1%	38	8.4%	**.039**	113	11.5%	24	8.3%	.118
Self-rated health	2.03	.91	2.14	.94	**.030**	2.06	.92	2.13	.93	.198
Health Utilities Index	.86	.18	.86	.18	.731	.86	.18	.86	.18	.955
Chronic Conditions	1.13	.79	1.12	.83	.839	1.14	.79	1.09	.86	.454
Major Health Events	.28	.52	.28	.52	.937	.29	.52	.27	.52	.503
Graduate FACP T1						770	73.1%	97	30.6%	**.000**
Graduate IACP T1	770	88.8%	284	56.3%	**.000**					

Spouse FACP	733	85.3%	153	30.4%	**.000**	756	72.1%	134	41.9%	**.000**
Spouse IACP	740	85.5%	293	58.3%	**.000**	866	82.0%	171	53.6%	**.000**
Sibling FACP	561	64.9%	290	57.8%	**.009**	670	63.6%	183	57.4%	**.045**
Sibling IACP	663	76.6%	343	68.1%	**.001**	801	75.8%	208	65.2%	**.000**

Table 3: Means (SD) and counts (%) for graduates in complete triads with no ACP at Time 1 by ACP status at Time 2 (n=424 formal ACP; n=259 informal ACP).

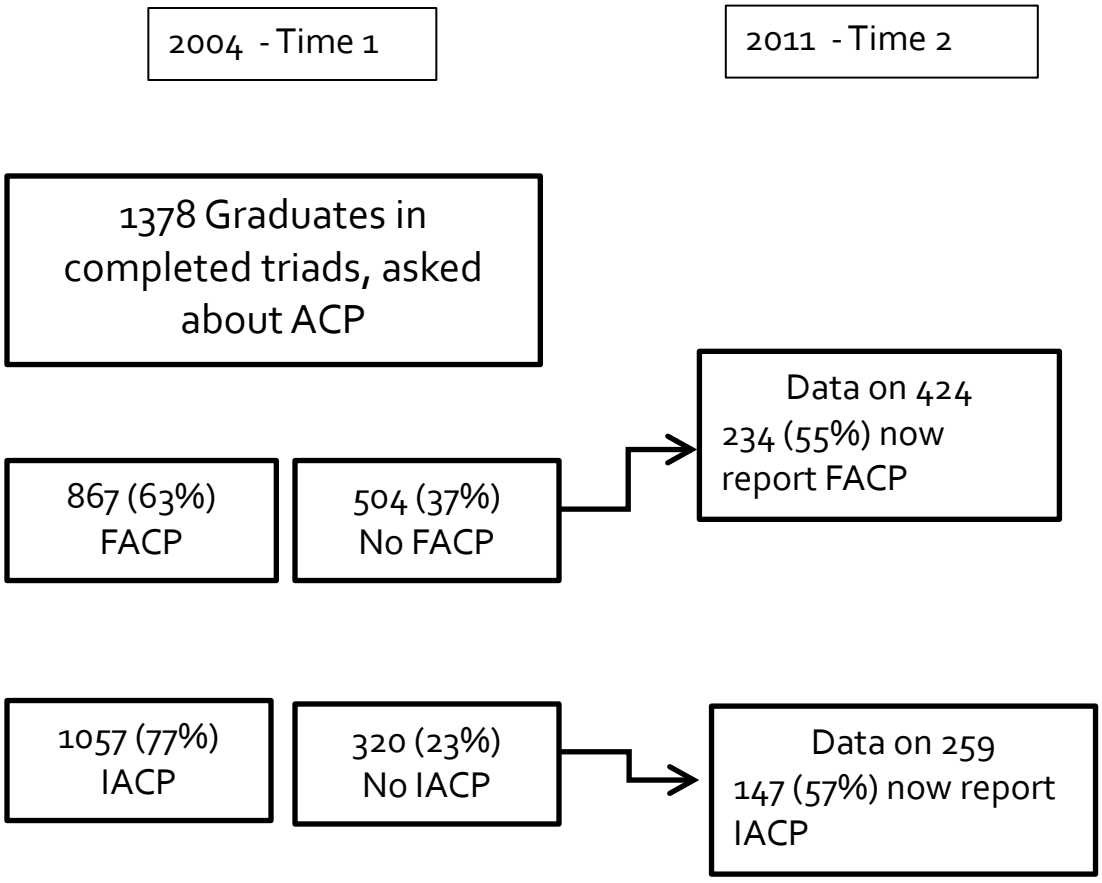
	Formal ACP Time 2 (n=234)		No Formal ACP Time 2 (n=190)			Informal ACP Time 2 (n=147)		No Informal ACP Time 2 (n=112)		
	# or M	% or SD	# or M	% or SD	sig.	# or M	% or SD	# or M	% or SD	sig.
Female	123	52.6%	77	40.5%	**.014**	58	39.5%	40	35.7%	.538
Age	64.27	.62	64.15	.68	**.058**	64.22	.64	64.34	.70	.172
Education	13.77	2.38	13.64	2.41	.571	13.69	2.40	13.50	2.31	.529
Number of children	3.41	1.85	3.39	1.75	.926	3.31	1.71	3.39	1.72	.710
Closeness to spouse	3.79	.43	3.78	.44	.862	3.76	.43	3.71	.49	.479
Closeness to sibling	1.82	.83	1.93	.79	.144	2.00	.75	1.82	.77	.062
Contact with Sibling in past yr					.361					.568
Never	7	3.0%	9	4.7%		8	5.4%	5	4.5%	
Once	9	3.9%	8	4.2%		6	4.1%	4	3.6%	
Twice	7	3.0%	8	4.2%		5	3.4%	4	3.6%	
3-5 times	31	13.5%	30	15.8%		20	13.6%	20	17.9%	
6-11 times	23	10.0%	25	13.2%		17	11.6%	11	9.8%	
12-23 times	50	21.7%	48	25.3%		35	23.8%	22	19.6%	
24-51 times	41	17.8%	29	15.3%		28	19.0%	14	12.5%	
>51 times	62	27.0%	33	17.4%		28	19.0%	32	28.6%	
Conscientiousness	4.76	.70	4.81	.67	.469	4.76	.67	4.73	.69	.732
Death avoidance	3.96	1.31	3.66	1.33	**.026**	3.84	1.32	3.17	1.36	**.000**
Physician control beliefs	3.55	1.13	3.49	1.09	.640	3.54	1.13	3.12	1.04	**.004**
Hospitalizations	18	8.3%	10	5.8%	.355	15	10.9%	5	5.0%	.103
Self-rated health	2.18	.95	2.07	.91	.246	2.18	.97	2.04	.92	.213
Health Utilities Index	.85	.19	.89	.15	.065	.85	.19	.87	.17	.452
Chronic Conditions	1.12	.81	1.14	.84	.836	1.19	.82	.90	.84	**.007**
Major Health Events	.30	.53	.25	.52	.325	.29	.49	.23	.54	.407
Was Widowed T1 to T2	16	6.8%	4	2.1%	**.022**	6	4.1%	10	8.9%	.108

Parental Death T1 to T2	41	17.5%	41	21.6%	.293	32	21.8%	23	20.5%	.810
Graduate FACP T1						47	32.6%	25	22.3%	.069
Graduate IACP T1	157	67.1%	84	44.2%	**.000**					
Spouse FACP	80	34.2%	46	24.2%	**.025**	63	42.9%	39	34.8%	.190
Spouse IACP	148	63.5%	104	54.7%	.067	82	56.2%	58	51.8%	.484
Sibling FACP	135	57.9%	102	54.0%	.414	82	55.8%	63	56.8%	.876
Sibling IACP	166	70.9%	122	64.2%	.140	102	69.9%	65	58.0%	**.049**

Table 4. Results of binary logistic regressions predicting Time 1 formal and informal ACP and Time 2 formal and informal ACP, for graduates without ACP at Time 1

	All Respondents at Time 1		Respondents with no ACP at Time 1	
	FACP	IACP	T2 FACP	T2 IACP
Sex	0.662*	1.479*	1.413	1.397
Age	1.144	0.939	1.423^	1.023
Education	1.078*	1.083*	1.021	0.977
Number of children	0.948	0.996	0.992	0.951
Closeness to spouse	1.471^	1.621*	0.976	1.842
Closeness to sibling	1.339*	1.108	1.069	1.911*
Contact with Sibling	1.072	1.04	1.12	1.017
Conscientiousness	1.166	1.225^	0.912	0.806
Death avoidance	1.076	1.253***	1.083	1.371*
Physician control beliefs	1.07	1.127^	1.004	1.508*
Hospitalizations	1.349	1.445	0.808	3.501^
Self-rated health	0.895	0.936	0.979	1.009
Health Utilities Index	0.536	0.846	0.138*	4.483
Chronic Conditions	1.063	1.131	0.778	1.891**
Major Health Events	0.916	0.962	1.195	1.078
Was Widowed T1 to T2			2.904	0.245^
Parental Death T1 to T2			0.971	1.46
Graduate FACP T1				1.517
Graduate IACP T1			2.355***	
Spouse FACP	12.687***	2.356***	3.19**	1.77
Spouse IACP	1.547*	2.88***	1.215	0.749
Sibling FACP	1.218	0.961	1.775^	0.546
Sibling IACP	1.159	1.718**	1.035	1.622
Spouse and Sibling both have FACP			0.258*	
Constant	0	0.151	0	0
-2 LL	1064.089	1013.696	425.805	228.173
Cox & Snell R Square	.303	.147	.128	.216
Nagelkerke R Square	.417	.226	.171	.290
included in analysis	1136	1142	345	204
missing cases	242	236	80	55
total	1378	1378	425	259

Figure 1. Respondents by ACP status at Time 1 with Time 2 response and ACP status



CHAPTER 4

IMPLICATIONS FOR FUTURE RESEARCH

This dissertation compiled three papers that, in different ways, seek to advance research on palliative and end-of-life care. The first chapter, reporting on the Thought Leader Survey, was research *about* research, and was motivated by the questions: What should palliative care researchers be studying, and what is holding the field back from answering the most pressing questions? The second and third chapters focused on individuals who were (or were not) making plans for the end of life. In the latter two papers, I conceptualized ACP as a health behavior and tested hypotheses derived from theories that propose key factors in health behavior change (i.e. the Health Belief Model's cues to action and social diffusion). In this final chapter I attempt to make connections between the results of the three papers and propose directions for future research.

In the preface and in the discussion in Chapter 1, I proposed a few ways that the results of the Thought Leader Survey serve as a foundation for additional research on ACP in Chapters 2 and 3. For example, despite only six respondents specifically naming ACP as a priority area for future research, many respondents recommended more research on communication and social/cultural perception of the topic of death and dying. Other research agendas have combined the topics of ACP with communication in general. Similar to the way in which completion of advance directives as a focus of research has gone out of vogue (Teno, 2004), thought leaders' recommendation to do more research on communication likely encompassed general doctor-patient and caregiver-patient conversations on important end-of-life topics without explicitly naming ACP.

The Thought Leader survey and the subsequent chapters on ACP focused on

the responses and actions of individuals, but the findings of all three papers also share an emphasis on the ecological context of end-of-life issues. For example, thought leaders recommended more research on caregivers, interactions between patients and professional caregivers, health systems, and how contexts of care or patient characteristics mediate or moderate effects; the focus was beyond the patient and his or her condition, extending instead to the family, institution, and community levels. In Chapters 2 and 3, I explored how health, health events, and family members' ACP status affect an individual's likelihood of ACP cross-sectionally and over time, with the strongest predictors of planning being family relationships and the planning status of close others.

In particular, applying the theory of social diffusion to ACP, in the third chapter, indirectly responded to the spirit of the thought leaders' recommendations. Their emphasis on the connected nature of patients, families, and health systems, was reflected in my hypotheses that ACP is affected by whether or not one's spouse or sibling has done planning. The results of that analysis -- in particular, the attenuating effect on a non-planner graduate's likelihood of formal ACP when having both a spouse and sibling with formal ACP at Time 1 -- speak to the importance and interplay of individual and contextual factors in an individual's decision to engage in planning end-of-life health care.

Chapters 2 and 3 use the same dataset and similar methods to test hypotheses about the factors that facilitate or trigger ACP. Results in Chapter 2 indicated that different dimensions of health are related to ACP differently. For example, number of chronic conditions was associated with informal ACP cross-sectionally, and more

chronic conditions at baseline predicted a greater likelihood of Time 2 informal but not formal ACP for non-planners. In contrast, baseline functional status (as measured by Health Utility Index) was not significantly associated with formal ACP cross-sectionally, but predicted Time 2 formal but not informal ACP in non-planners. The results of the analysis in Chapter 3 suggest a strong cross-sectional association of the ACP status of an individual's spouse and sibling on the likelihood of planning, and a strong effect of both spouse and sibling status on formal ACP over time. Based on the findings and limitations of the findings of these two papers, I propose several areas for future research.

1. Health status of close others as predictor of ACP

A logical extension of the findings of the two papers on ACP is to investigate how the health or health events of a spouse or sibling affect the focal individual's likelihood of ACP. If a major health event or hospitalization triggers formal ACP in a married person, and formal ACP tends to be shared between spouses, it follows that the health of one's spouse would likely affect one's ACP status. Future research that controls for health status of close family members may produce more accurate predictions of likelihood of ACP. If health status or illness of close others triggers ACP in focal individuals, it is possible that health or illness rather than contact and conversations are an essential element of social diffusion of ACP. If being sick makes people plan, perhaps witnessing the illness of close others has a similar effect.

2. Research on existing ACP educational interventions

The results of the analyses in Chapters 2 and 3 identify personal and social factors (i.e. planning status of spouse and sibling) that appear to predispose some people to do ACP. However, there are several popular programs and curricula that seek to educate about ACP and help individuals complete formal and informal plans -- for example, Respecting Choices, the Caring Conversations Workbook, and the Five Wishes, among other programs (list maintained by the CDC available at http://www.cdc.gov/aging/pdf/acp-resources-public.pdf). Some of these programs have been evaluated, but across different patient populations and with differing outcomes of interest. All, however, are being used by hospital systems and/or community groups with very little sense of their effectiveness in changing planning behavior. It appears that most older adults are completing ACP without the support of educational programs. Therefore, if educational programs like the Five Wishes wish to demonstrate real impact, rigorous evaluation is needed to prove that people who would not have done planning otherwise are completing ACP through these programs. The findings presented above suggest that there are persistent non-planners. ACP education and assistance may be a welcomed support for people who are interested in and intending to complete ACP, but the effect of these programs to convert non-planners is unknown.

In addition to the effectiveness of popular ACP education programs, research on ACP could benefit from a content analysis of existing curricula that educate about and encourage ACP. Existing programs are likely based on an implicit theory of change or working explanatory model of the factors that facilitate ACP in older adults. Understanding how these popular methods to boost ACP do or do not align with the

research literature on who undertakes planning and how planning is decided may suggest fruitful directions for research on ACP. In addition, if program strategies and the research literature are misaligned, pathways for dissemination of research to practice may be needed.

3. Novel interventions to encourage and support ACP

The research base on characteristics of individuals who engage in ACP could be leveraged to develop screening or targeting criteria to strategically deliver supportive interventions to people least likely to complete ACP on their own. For example, ACP education is universally offered to people who are admitted to hospitals, but individuals with multiple chronic conditions that are managed in an outpatient setting may also welcome information or support in completing ACP. The analysis in Chapter 2 suggests that people with chronic conditions are more likely to do planning in general, but higher completion rates in this population might be seen with targeted interventions.

The unexpected main effect of closeness (with a spouse or with a sibling) on the likelihood of completing formal and informal ACP suggests that people who are socially isolated may be at risk for not completing ACP. This interpretation is consistent with the finding in Chapter 2 that being a widow is associated with ACP cross-sectionally, but that becoming a widow reduces the likelihood that a non-planner will go on to complete information ACP by Time 2. Informal ACP, by definition, requires a person with whom to discuss end-of-life health care preferences. It follows that the loss of a spouse effectively removes a major opportunity for having a

discussion about end-of-life wishes with a close other. Developing interventions that target people with no or few confidants may be an effective pathway to increase rates of ACP in persistent non-planners.

An important area of inquiry not addressed by these papers is the adequacy of ACP for people who report having plans in place. Practitioners and public health advocates concerned with end-of-life health care must move beyond a binary understanding of ACP in which high rates of "yes" responses signal a lack of need for planning support. Given the relatively high rates of planning among older adults, interventions and supports for ACP should consider focusing on improving the quality of existing plans, raising the standard of ACP to ensure that they are thorough and frequently revisited to respond to an individual's changing circumstances.

4. Research on representative populations and older middle aged/young older adults

There are limitations associated with the respondents and measures available in the dataset (Wisconsin Longitudinal Study). More research is needed on racially and ethnically diverse populations, people in different regions of the country, and on older middle aged adults (i.e. 55-64). At Time 1, when respondents were about 64 years old, most had already done formal and informal ACP. People who have not done planning by age 65 may therefore be qualitatively different than the general population; individuals who "hold out" and resist planning until older adulthood may represent a special case, albeit one that is still worthy of study, if we hope to persuade them to do planning before they die. With regard to racial, ethnic, and regional diversity, there are important and unanswered questions about the universality of factors that affect the

likelihood of planning. Nationally representative datasets that incorporate questions on ACP, like the newly available 2012 Health and Retirement Study, will provide the opportunity to explore these issues.

5. Research on the morphology of ACP discussion

A substantial portion of the research in this dissertation focuses on outcomes that were measured with extremely simplistic questions. The results presented above are not entirely without merit, but research on ACP must move beyond brief, binary questions about whether or not someone had a discussion or has a living will or Durable Power of Attorney for Health Care. Extremely little is known about the morphology of ACP processes and discussion. For example, who initiates conversations, how long they last, how detailed they are, what events or reasons do people report for broaching the topic, and the like. Understanding the range of ACP processes could be useful for intervention development, clinical interactions, and even within-family conversations about end-of-life wishes. Moreover, although my choice to model formal and informal ACP as separate outcomes was based in prior research, understanding these two processes as separate and parallel is perhaps not true for every case. More accurate predictions of likelihood of planning and targeting of likely non-planners would benefit from a typology or more sophisticated understanding of how individual seek information, decide to do planning, initiate conversations, and complete legal documents.

There are many rich sources of information on the issues surrounding end-of-life care, but many more unanswered questions. The proliferation of research agendas

for palliative care, including the one presented in the first chapter, are motivated by a sense that this diffuse field needs to build connections between the people and institutions doing and funding the research. Research in palliative care is certainly motivated by the needs of clinical practice, but at least in the case of ACP, strong connections between research and practice are not evident. There is an unrealized potential to promote an open and informed conversation about end-of-life by developing programs or targeting education based on research, and there are likely fruitful areas for research that would be suggested by practitioners and patients who are experiencing serious illness and/or who are involved with palliative care. Future research on ACP should pursue the several areas described above, and in doing so could lead other sub-areas of palliative care into thoughtful translation of research into practice, and intentional learning from practice to guide research.

References

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